

Social integration of people with intellectual disabilities in neighbourhoods: sitting on the fence

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Social integration of people with
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PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit Maastricht,
op gezag van de Rector Magnificus,
Prof. mr. G.P.M.F. Mols
volgens het besluit van het College van Decanen,
in het openbaar te verdedigen
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door

Laura Maria van Alphen

Promotores:

Prof. dr. L.M.G. Curfs

Prof. dr. H.W. van den Borne

Copromotor:

Dr. A.J.M. Dijker

Beoordelingscommissie:

Prof. dr. G. Kok (voorzitter)

Prof. dr. J.D.M. van der Geest (UVA)

Prof. dr. J.P.M. Geraedts

Prof. dr. H.P. Meininger (VU)

Prof. dr. N.K. de Vries

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Chapter 1

General Introduction

Tuesday April 10, 2007 a daily Dutch newspaper ran the headline “The intellectually disabled move back to the institution” (Ley, 2007, April 10), reporting on the decision of a Dutch care organisation to return some of their clients with intellectual disability (ID) living in small houses in regular neighbourhoods back into institutional care. Painting a bleak picture of the possibilities of people with ID living in those community homes, the author concludes that “integration into society can now considered to be a failure” (Ley, 2007, April 10). Yet, other stories of people with ID living in normal neighbourhoods show different experiences; that of people exploring new horizons, making friends, and seemingly being satisfied with their living arrangements in smaller community homes (Gregory, Robertson, Kessissoglou, Emerson & Hatton, 2001):

I get on quite well with the residents and get on quite well with friends at work. [I] have acquaintances that I see when I’m down at the [local pub]... [I] pop up to see [mum] with my keyworker (p.286).

Social integration of people with ID is currently a hot topic now the effects of ‘care in the community’ policies are evaluated. ‘Care in the community’ refers to the provision of care in small scale housing facilities in regular neighbourhoods, as opposed to care in traditional, larger institutions separated from ‘normal’ society, a policy change that has been stimulated in the Netherlands since the 1990s (Ministry of Health Welfare and Sports, 1995). ‘Care in the community’ represented a shift in thinking about care which contradicted the then dominant focus on medicated and segregated care for people with ID and people with psychiatric problems (the ‘anti-psychiatry movement’, Duyvendak & Verplanke, 2010). Care policies for other social groups such as elderly people or people with physical disabilities are also changing, with an increasing focus on possibilities for community care under the Social Support Act (‘Wet Maatschappelijke Ondersteuning’, Ministry of Health Welfare and Sports, 2004).

In popular media such as newspapers and TV reports, often a sense of disappointment with the outcomes of ‘care in the community’ for people with ID is expressed. For example, parents of people with ID and others affected by this policy are sometimes voicing their concerns about the provision of proper care (Malsch, 2006, February 27; Vermeulen, 2007, April 11) and providing freedom of choice to, while simultaneously protecting those they see as vulnerable (Zembla, 2007, May 20). However, most disappointment seems to relate to either the blatant rejection by prospective neighbours to the arrival of

people with ID (or other stigmatised groups) in a neighbourhood (Visser, 2008, September 20) or the lack of meaningful relationships that were expected to develop with people with ID and other members of society without ID, including neighbours (Duyvendak & Verplanke, 2006, January 14; Vermeulen, 2007, April 6).

Social relationships between people with ID and others in the wider society are an important part of 'community care'. Reinders (2002) verbalises the importance of focussing on relationships as a vital ingredient: "Community living is an experience, not a location [...] [it] is the experience of sharing one's life with people" (p. 2). However, it is not only the voluntary relationships with the people one chooses that are important to one's quality of life (such as family members, volunteers or other people with ID), but also the more or less involuntary relationships with the people one is thrown into contact with that have an effect on one's personal well-being. Neighbours are especially overlooked in this context; they seem to either be considered a nuisance when they are opposing the siting of a community home (Dear, 1992; Hudson-Allez & Barrett, 1996; Zippay, 2007), or a promising potential for social contacts that often fails to deliver (Cook, 1998; Cummins & Lau, 2003; McConkey, Noonan Walsh & Conneally, 1993; Myers, Ager, Kerr & Myles, 1998). Much could therefore be gained in terms of well-being and quality of life of both people with ID and their neighbours, by studying the social interactions and relationships that they have and how they are experienced on both sides of the fence.

When discussing the assumed lack of social integration, it may be tempting for policy makers or researchers to make normative statements about social integration. Looking at the discussions in popular media, different levels, or definitions, of social integration are postulated, and often assumptions are made, for example, about the needs of people with ID in terms of social contacts in neighbourhoods, or about the character of modern society, assumed to be unwilling to accept or interact with those perceived as different. When what actually happens during interactions between people with and without ID in social settings such as neighbourhoods, in terms of thoughts, emotions or needs of those involved, is overlooked in favour of politically charged opinions, it may not be so surprising to occasionally detect some disappointment.

In this study we approach social integration from a social psychological perspective. This perspective allows us to study the way neighbours with and without ID interact in everyday social situations. Paying close attention to the thoughts, emotions and behaviours of both, and the way in which they

influence each other, we want to generate a realistic description of social interactions between neighbours with and without ID, free from any assumptions or norms formulated by third parties. Like any other integration issue between members of different social groups, it is important to understand the experiences and desires of both parties in the equation to be able to make any valid statements about social integration. We make a distinction between the thoughts and emotions of people without ID anticipating contact with people with ID in a pre-contact phase, and the thoughts, emotions and mutual interaction needs of both neighbours with and without ID in actual social interaction with each other. This way, we want to understand more of the complex nature of social integration in the particular setting of modern neighbourhoods.

In this introduction, first, we will pay attention to the background of community care for people with ID. We briefly outline the history of deconcentration and the development of community care policies for people with ID in the latter half of the last century. ‘Community Care’ is a policy concept that seems to have no uniform meaning, and may refer to different living and care arrangements. Subsequently, these differences and the degree of implementation of community care policies in Europe will be described. Then, we give a short description of the various effects of community care, as evaluative studies focus on a variety of quality of life outcomes, including social integration. However, the concept of social integration is rather vague. In the following section we contemplate what can actually be understood by social integration of people with ID, before outlining how social integration of people with ID in specifically neighbourhoods has been studied up until now, and where it may have failed to sufficiently address the complex nature of social interactions between people with and without ID. In the closing part of this introduction, the approach used in this study will be presented, and how it may contribute to further understanding of social integration of people with ID in neighbourhoods.

A short history of deconcentration of care for people with ID

The Netherlands in the twentieth century had a long tradition of institutional care for people with ID. These institutions were often in fenced off large campus settings, situated ‘in te countryside’ separate from regular society, in which life was organised by set (medical) routines (Beltman, 2001; Duyvendak & Verplanke, 2010; Overkamp, 2000; Schuurman, 2002). Care policies such as these can be seen as a product of the perception of people with ID at the time (Beltman, 2001). At this time, around the earlier half of the last century, the

medical model of disability was predominantly used in care policies, in which people with ID were foremost perceived as patients (e.g. Beltman, 2001; LoBianco & Sheppard-Jones, 2007). The medical model defines disability as a biological defect within an individual, limiting this person in his functioning. For people with ID, according to this medical model, no improvement would be possible (as the biological defect would be permanent), and the proper response would be providing continuous, but constricted, care. In practise, this meant that medical doctors and psychiatrists were responsible for care, guarding the peace, order and rhythm of the day (Duyvendak & Verplanke, 2010).

The perception of people with ID as medical patients and, based on this perception, the organisation of care in institutions were challenged in the latter half of the twentieth century. Institutional life for people with a variety of socially undesirable conditions was critiqued by several authors including sociologist Erving Goffman (1961). He describes how inmates of 'total institutions' (using mostly people with a mental illness or prisoners as examples) were stripped of their individual social roles (i.e. son, husband, mother, co-worker), and reduced to a patient or inmate role. His view, among others, inspired the anti-psychiatry movement in the Netherlands (Beltman, 2001; Duyvendak & Verplanke, 2010) and jump-started a different way of thinking about disabilities and long term care.

Recognising the struggle of people with disabilities for their civil rights under the medical model, disability (self-) advocates proposed the social model of disability. The social model makes a clear distinction between *impairment* (the physical consequence of pathology), *disability* (the functional limitations experienced as a consequence of impairment) and finally *handicap* (the (social) disadvantage experienced by individuals when functional limitations stop them from fulfilling their social roles). By making this distinction, it holds society responsible for the experience of a handicap, rather than perceiving it intrinsic to a person (Bickenbach, Chatterji, Badley & Üstün, 1999; Burchardt, 2004). It is thought that society's inappropriate response to impairment (by discrimination, segregation and social control in an abnormal care environment) limits people with a disability in their possibilities to live as normal citizens, and perform normal social roles; were society to respond adequately to disability, handicap as such would not exist.

The principle of normalisation, introduced in Scandinavia by disability advocate Bengt Nirje, was developed to normalise a care environment and allow for individual personhood of people with ID (Perske, 2004). The principle of normalisation has several pillars on which a care environment is to

be normalised; observing normal rhythms of the day, year and cycle of life, allowing for individual choice, normal economic standards, normal social and romantic relationships and most importantly; living, learning and recreating together with other people in society. This last pillar refers to the identification of people with ID as people first and their need to integrate in normal society alongside other people and not pass their lives in a separate, closed world consisting of just them, their peers and their carers.

The principle of normalisation and citizenship, and the focus on quality of life have been the main drive behind the deconcentration of care organisations for people with ID in the Netherlands in the 1960s and 1970s (Beltman, 2001; Duyvendak & Verplanke, 2010; Kröber, 2008; Overkamp, 2000). Large care organisations in the Netherlands have been stimulated by changing care laws such as the Social Support Act (Ministry of Health Welfare and Sports, 2004) to move many of their clients with ID from their campus grounds and integrate them into society. This is following a similar and simultaneous trend of care development in other countries, such as those in Scandinavia, the UK and the USA (Hamlin & Oakes, 2008; Mansell, 2006; Mansell, Knapp, Beadle-Brown & Beecham, 2007; Meyer, 2004; Tossebro, 1998) and is formalised in mission statements such as the WHO Europe mission statement to reduce or eradicate institutionalised care completely (World Health Organisation, 2010).

Following these changes, the definition of people with disabilities in general (ICF, World Health Organisation, 2001), and ID in particular (Schalock et al., 2010), has moved from a rather narrow to a broad definition that incorporates the many social, behavioural, and functional aspects of (intellectual) disability. For a current definition, see box 1.1.

Box 1.1 Definition of intellectual disability

There are many approaches to conceptualising and characterising intellectual disability (or other often used terms such as learning disability) and its social consequences from different fields of study (e.g. Bickenbach et al., 1999; Dowse, 2009; Goodey, 2001; McClimens, 2007; Vehmas, 2004). The American Association on Intellectual and Developmental Disabilities (Schalock et al., 2010) defines intellectual disability in a broad sense, and is widely used as the authoritative definition of intellectual disability today:

Intellectual disability is characterised by significant limitations both in intellectual functioning and in adaptive behaviors as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. The following five assumptions are essential to the application of this definition:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve. (p.1)

This definition reflects the change in perception of people with ID from a person-centred trait or limitation to a definition incorporating all facets of human functioning in interaction with their (social) environment. The five assumptions further underline this: ID should be considered (1) within the varied (social, formal) contexts of the individual, (2) the individuals' culture and customs, and (3) recognise individual differences in possibilities and limitations. Additionally, the label (4) should lead to identifying possibilities for support and (5) proper support should improve an individuals' functioning.

Two to three percent of the population has some form of intellectual disability, with the majority (75% to 90%) having mild ID, and smaller groups (10% to 25%) having moderate, severe or profound ID (Daily, Ardinger & Holmes, 2000). Briefly, mild ID is characterised by an IQ of 50 to 70, slow development and the ability to acquire some practical cognitive and social skills. People with moderate ID have an IQ of 35 to 49, have noticeable developmental delays, may have physical abnormalities, and can develop some skills in simple activities such as basic health and self-care. People with severe ID have an IQ of 20 to 34, have obvious developmental delays, little or no communication skills but can show some understanding and need direction and supervision. People with profound ID have an IQ below 20, show marked delays and need close supervision, and often attendant care. Intellectual disability is most often caused by a chromosome abnormality, but congenital infections, metabolic disorders, environmental and/or multiple factors are known. However, very often (30 to 50% of all cases), the cause remains unknown or unclear.

In the province of Limburg, the prevalence of people with ID is 0.64 to 0.70% determined by general practice data bases and service registrations (Van Schroyen Lantman-de Valk, Wullink, Van den Akker, Van Heurn-Nijsten, Metsemakers & Dinant, 2006). (For an estimation to extrapolate this to the Netherlands, see Wullink, van Schroyen Lantman-de Valk, Dinant & Metsemakers, 2007). It is estimated that of the approximate 111.750 people with ID in the Netherlands, 53.000 are in residential care, and 58.000 live with their parents or independently (Raad voor Gezondheids-onderzoek, 2005).

Deinstitutionalisation and community care in Europe

In many European countries a process of deinstitutionalisation for people with ID is taking place (Mansell et al., 2007). Deinstitutionalisation does not always refer to the same process, however. Although the predominant form of deconcentration refers to people with ID moving from institutional grounds into existing neighbourhoods (Mansell & Beadle-Brown, 2009b), other developments of de-institutionalisation are also known. For example, in intentional communities (sometimes referred to as 'reverse integration') people without ID move purposely into old campus grounds where people with ID already live (Severinus, 2009).

The intended result of deinstitutionalisation is some form of community care, but this does not mean that community care has a universal appearance (Kozma, Mansell & Beadle-Brown, 2009). It is possible to see forms of community care on a scale of highly institutional in character (despite being the result of relocation from institutional grounds) to highly integrated in character. It may refer to people with ID living in regular single-family houses, purpose-build houses, clustered ('congregate') houses, or apartments. People with ID may live alone, for example in supported living arrangements, in which they live as independent renters or home-owners contracting care from an organisation. More often, however, they live with a small group of housemates greatly varying in size (generally from 2 up to 18) (Kozma et al., 2009), and often in congregate settings (Hamlin & Oakes, 2008). Staffing may vary as well; depending on the support needs of the people with ID, staff may visit occasionally, periodically, or be present full-time (Hamlin & Oakes, 2008; Mansell et al., 2007). With these differences in care provisions, it is hard to give an estimation of people with ID currently living in community care facilities in Europe.

As different as community care projects in appearance are, there is a consensus about factors commonly associated with institutional care; the typical large number of non-family members living together, segregated from the wider society in a depersonalised environment characterised by routines and lack of personal choice (World Health Organisation, 2010). Successful community care aims for the opposite of that; accommodation among the rest of society, adapted to the individuals' needs and wishes, enabling them to make their own life decisions and participate fully in society. However, deinstitutionalisation and the implementation of community care is not a fluent process. There is a considerable gap between the ideology of community care and daily practices in services for people with ID (Mansell & Beadle-Brown, 2010; McNally, 2004; Overkamp, 2002). Even in small scale community

homes, daily routines may be of an institutional nature, that is, highly directed by staff and organisational practices and habits rather than directed by the residents with ID themselves. Small scale community facilities may also bear some physical aspects that are often associated with institutions (e.g. functional hospital-style furniture, fences, and an office). It is therefore proposed that deinstitutionalisation as a process is more than a change of location; it involves the culture, discourse and habits of an organisation (Hamlin & Oakes, 2008; Mansell & Beadle-Brown, 2010; Overkamp, 2002; World Health Organisation, 2010). Community care thus seems to entail more than just a move from segregated, institutional care to care in regular neighbourhoods, and this seems to be a continuous point of concern.

Box 1.2 Case study Pergamijn

Stichting Pergamijn is a care organisation for people with intellectual disabilities in the Dutch province of Limburg. In 2002, Stichting Pergamijn (in that time called 'Pepijn and Paulus') started a process of deinstitutionalisation to realise possibilities for their clients to live a life 'under as normal circumstances as possible' in regular houses in regular neighbourhoods. Pergamijn's aim is assisting people with intellectual disabilities to make use of the full potential of their choices, chances and opportunities. Recognising that people with ID belong in society, but need support to be able to do so, Pergamijn organises resources to assist their clients in residing, working and recreating in a way which befits their individual needs.

Currently, Pergamijn offers support to nearly 800 residential clients and provides day-care facilities to 200 clients. Pergamijn has build apartments, studios and sheltered housing facilities and eventually plans to support about 650 clients in regular neighbourhoods. In 2010, 40 houses and 72 apartments and studios were build and running, some of these included clustered homes or apartments. Clients live with a maximum of 5 housemates in a single home, and the total group of clients in clustered housing facilities is on average 16 (8 to 27). Clients get support from staff either full-time or periodically. Staffing and support of this majority is dependent on the level of ID of the residents, which can be considered mild in 1 house, moderate in 11, moderate to severe in 12 and severe in 5 houses. Pergamijn still offers sheltered accommodation on their old institutional grounds. At the end of the deinstitutionalisation process there will be about 200 places for clients wishing to remain living there or needing additional specialised support (people with severe ID or with additional behavioural problems). Pergamijn will further continue its commitment to deconcentration in the next few years.

Next to offering residential care, either in regular neighbourhood housing facilities or on institutional grounds, Pergamijn offers employment in sheltered work or mediation in finding work on the regular marked, recreation in the form of organised social activities, and therapeutic and medical care where needed. Interested in sharing and further developing their scientific knowledge surrounding support for people with ID, Pergamijn has started collaborating with Maastricht University - Gouverneur

Kremers Centre, of which the current project is part of the Pergamijn – GKC research programme ‘living in regular neighbourhoods’.

Studying the effects of ‘care in the community’

Relocation to a regular neighbourhood is not a goal in itself, but rather a means to improve overall well-being and quality of life of people with ID. Institutionalisation was associated with harmful effects, such as poor physical health and hygiene, delayed or stagnated (brain) development, elevated anxiety and behavioural disorders, inability to form healthy emotional relationships and overall reduced life chances (World Health Organisation, 2010). Research into the effects of community care has therefore focussed on improvements in life in broad terms. While overall quality of life of people living in small scale care facilities in regular neighbourhoods seems to have improved, the picture is not at all conclusive and rather complex (e.g. Kozma et al., 2009).

Interestingly, and as mentioned earlier, people with ID who have moved out of residential care into community care facilities (and their families) often report high satisfaction with their current living arrangements, even though some were sceptic about or opposed the move initially (Gregory et al., 2001; Tossebro, 1998). However, it could be argued that only focussing on subjective measures of life satisfaction might give a deceptive picture. Cummins (2001), for example, describes the risk of relying on subjective measures of life satisfaction. He states that people’s life satisfaction generally stays within normal range (and unconsciously so) in various life circumstances, and is only affected under very severe or adverse circumstances. The reported satisfaction of people with ID living in community homes is then hard to interpret; it could be that they are indeed content with their living arrangements in the community, it could also mean they have adapted to their changed situation.

Researchers thus evaluate the effects of community care in various terms of quality of life, including both objective and subjective measures (Schalock et al., 2002; Verdugo, Schalock, Keith & Standcliffe, 2005). While there is still much discussion on the conceptualisation and proper measurement of quality of life an important agreement is that quality of life is a multi-dimensional concept that includes measurements in various life domains. Incorporating both objective and subjective measurements does justice to both the individuals’ context (e.g. national averages in number of social contacts) and personal experience (e.g. individual wishes for social contacts). While quality of life

studies may include different indicators, e.g. depending on cultural context, eight core domains can be recognised (Schalock et al., 2005), focussing on emotional, interpersonal, material and physical wellbeing, personal development, rights and choice, and finally, social inclusion.

In a recent extensive review of 68 evaluative studies comparing people with ID living in various institutional care facilities with people with ID living in community care facilities, Kozma, Mansell and Beadle-Brown (2009) systematically outline the effects of community care in various areas. While overall quality of life of people with ID relocating to community care facilities improved, results often remained inconclusive, and were mediated by different factors besides just a move to a community, such as individual characteristics, staff practices or service procedures.

For example, concerning health outcomes, people with ID moving out of residential care showed no direct aversive effects in terms of mortality, but while they had a higher rate of activity which was related to better health outcomes, they also were more likely to make bad lifestyle choices (e.g. smoking, poor diet). Indeed, smaller community-based services more often allowed for more opportunities for self-determination and choice making than larger, congregate settings. However, this tended to involve rather small, every day decisions (such as diet choices) than major life choices, which were still often determined by staff or organisational considerations. Measurements of differences in reported adaptive skills, challenging behaviour and the use of psychotropic medication for people with ID in either residential or community care also yielded inconclusive results (Kozma et al., 2009).

People with ID generally express the wish for more social contacts and friends, and indeed, expanding social networks and developing friendships are important parts of well-being and an indicator of social inclusion (Emerson & McVilly, 2004; Kampert & Goreczny, 2007). People with ID living in small scale facilities generally do have larger social networks, more friendships, and report more community participation than people with ID living in residential or institutional care, but this seems often mediated by other factors than just relocation (Kozma et al., 2009). While smaller settings offer more opportunities for community involvement than traditional residential services, this finding seems mediated by an individual's social competence, adaptive behaviour and level of support needs. Additionally, these networks mostly involved staff, family members and other people with ID (Ager, Myers, Kerr, Myles & Green, 2001; Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001), and not often people from the wider community without ID. Moreover, limited social contacts and loneliness among people with ID living independently is

not unheard of (Bigby, 2008; Duyvendak & Verplanke, 2010; O'Rourke, Grey, Fuller & McClean, 2004).

In conclusion, it seems that deinstitutionalisation has brought positive quality of life outcomes for people with ID, though the picture often remains complex. Especially social integration, in terms of social contacts and relationships, seems to remain a challenge.

What is social integration?

The terms 'social integration', 'social inclusion' and 'participation' have been mentioned a few times, without having made explicit what is meant by them. Researchers often make a distinction between physical integration, functional integration and social integration. The first two refer to the act of moving from segregated care to care in local communities and using mainstream facilities in these communities rather than specialised services respectively. The latter remains a vague concept, is often differently defined with alternative terms such as 'social inclusion' and 'social participation', and as such seems the hardest to measure.

Since physical and functional integration are often seen as a necessary condition for social integration, the difference between these three 'degrees of integration' often gets blurred. Researchers may understand social integration to imply the degree of community activities one participates in (Collins & McConkey, 2007; Kozma et al., 2009; Thorn, Pittman, Myers & Slaughter, 2009), physical presence (Meyer, 2004) or experiencing freedom of choice (Murphy, 2009; Vine & Hamilton, 2005). Additionally, social contacts or supportive relationships with others in a community (Collins & McConkey, 2007; Forrester-Jones et al., 2006; McConkey, 2006; Verdonshot, Post, van der Pijl, Buntinx & van Gennep, 2005) which have a degree of reciprocity and mutual adaptation (Eikelboom & Finkenflügel, 2006; Overkamp, 2000) are also often used indicators of social integration. However, social integration incorporates facets of all these different definitions and measurements (e.g. Cummins & Lau, 2003; Myers et al., 1998). The opposite of social integration is relatively easier described: social exclusion or rejection, stigmatisation, separation, isolation, being devalued and disadvantaged are all direct opposites of social integration. Valuable relationships with others in a community, in which the person with ID is fully accepted and valued as a interaction partner, without denying their differences or limitations, is often considered to be the apex of social integration (Forrester-Jones et al., 2006; Kampert & Goreczny, 2007; Meininger, 2010).

Social integration in a neighbourhood setting

Research into neighbourhood social integration seems to have been predominantly concerned with promoting physical integration by way of eradicating opposition to people with ID moving into neighbourhoods. This approach is understandable, as neighbours play first and foremost the role of supporter or critic of community care, in the sense that they can choose to block (e.g. through petitions) people with ID moving into their neighbourhood. At the start of the implementation of community care policies, and perhaps even now, this was not a rare occurrence (Cnaan, Adler & Ramot, 1986; Wilmoth, Silver & Severy, 1987), and the focus in research thus often lays in understanding and overcoming this opposition. However, this approach may have serious shortcomings in fully understanding the complexities of social integration as it oversimplifies the issue; one of being positive or negative about the presence of people with ID in one's neighbourhood. Firstly, focussing only on neighbours' general attitude towards (physical) integration gives little insight into their specific reasons, in terms of thoughts, emotions and interaction needs, for opposing or supporting social contact with people with ID. Instead, attention to the underlying psychological mechanisms can help us understand more about neighbours' responses when they contemplate social contact with people with ID. Finally, measuring opposition or support alone would imply that neighbourhood social integration could be considered completed after merely successful relocation, which may refer to physical rather than social integration.

Exclusive attention to general attitudes obscures specific responses

As mentioned above, the approach in neighbourhood (social) integration research has predominantly focussed on measurements of general attitudes towards physical integration (i.e. support or opposition to the presence of people with ID in one's neighbourhood). However, general attitude measurements give little information about neighbours' motivation behind their responses, i.e. *why* they would respond positively or negatively to a home for people with ID in their street. This may lead to wrongful conclusions about strategies to overcome neighbourhood opposition and improve integration.

In measuring general attitudes towards having people with ID as neighbours, individual and neighbourhood demographics and previous contact experience with people with ID are two factors often taken into account. Firstly, some individual characteristics of neighbours have typically been related to being more likely to hold negative attitudes and oppose a home

for people with special needs, like being male, white, middle to upper-middle class, older, homeowner, having a high income and living with young children (Arens, 1993; Dear, 1992; Graham & Hogan, 1990; Wilmoth et al., 1987). However, the relationship between these characteristics and negative responses is often inconsistent in other research (e.g. Okolo & Guskin, 1984; Overkamp, 2000; Schwartz & Rabinovitz, 2001), and focussing on neighbourhood characteristics also provides little practical tools for improving integration as policy makers can neither select a neighbourhood based on them, nor change them.

Secondly, and more promising, studies overwhelmingly find that neighbours who have more contact with people with ID report more positive attitudes and support for community homes. Indeed, while people respond more negatively to the arrival of an actual group home in their street than those responding to a hypothetical group home, (Cook, 1998; Okolo & Guskin, 1984; Overkamp, 2000; Zsombok, Hammer & Rojahn, 1999), opposition tends to decrease over time (Arens, 1993; Barr, McConkey & McConaghie, 2003; Hudson-Allez & Barrett, 1996). Moreover, neighbours reporting more contact, e.g. by visiting or merely living closer to the home, are also more positive than those with less contact experience (Cook, 1997; Jason, Roberts & Olson, 2005; Pittock & Potts, 1988). This diminished opposition presumably occurs because neighbours have had the opportunity to experience the presence of people with ID and could adjust their initial negative thoughts and fears, which is considered the main concept behind the theory of intergroup contact (Allport, 1954/1979). In intergroup contact between members of different social groups, ingroup members have the chance to learn about members of a particular outgroup and change their opinions about them. While several conditions for optimal contact situations have been identified (e.g. equal status and support from authorities, Dovidio, Gaertner & Kawakami, 2003; Pettigrew, 1998), mere contact with members of a variety of social groups (e.g. ethnic minorities, people with different sexual preferences, and also people with disabilities) has been found to be beneficial in terms of reducing stigma and intergroup conflict (Pettigrew & Tropp, 2006).

While the positive relationship between contact and neighbours' general attitudes is indeed promising, three problems in its application to social integration issues may occur. Firstly, it may motivate policymakers to think that neighbours do not need to be involved in the process of relocating people with ID into a neighbourhood, as whatever opposition may arise will likely subdue when neighbours have had a chance to see that their initial fears are unfounded. Yet it is found that facilities that have opened 'silently' (i.e. not

informed neighbours), while encountering less opposition initially, run into more negative responses from neighbours in the long run (Zippay, 1997). This indicates the importance to involve neighbours as potential allies in the integration process, rather than potential enemies, and target education prior to the opening of a care facility to their specific needs (Cook, 1998; Hogan, 1986). This does mean that it is important to actually understand what these specific needs are. The second problem may lie in understanding the motivations behind the avoidance of contact altogether: Neighbours who successfully oppose the arrival of a group home, or who may, after a group home is established, avoid any further contact, likely will not benefit from (positive) contact experience. Finally, a change in general attitudes after contact does not give much insight in what this may mean in terms of specific thoughts about people with ID and related interaction needs. Does experience with the presence of a community home change any specific thoughts and emotions neighbours may have about people with ID, or about the policy of community care? Has contact experience with people with ID changed the way neighbours would like to interact with them?

In recognising that a distinction needs to be made between responses towards *people* with ID, and towards a *home* for people with ID, some studies do incorporate some measurements of specific thoughts about people with ID and (the policy of) community care (e.g. Cnaan et al., 1986; Cook, 1998; Henry, Keys, Jopp & Balcazar, 1996; Hudson-Allez & Barrett, 1996; McConkey et al., 1993; Pittock & Potts, 1988; Robertson et al., 2005; Schwartz & Rabinovitz, 2001; Wilmoth et al., 1987). Including these more specific belief measurements in research has yielded some interesting results. Overkamp (2000), for example, found that the fewer negative thoughts neighbours had about people with ID (e.g. 'people with ID are dangerous'), the more favourable their attitude was towards the presence of people with ID in their neighbourhood. In addition, in studying the effect of contact on beliefs, Overkamp found that neighbours of an existing home did not necessarily have a more positive, but rather showed a more nuanced view of people with ID: Compared with respondents who were not yet neighbours of people with ID who showed a 'positive bias' (i.e. agreed with more positive statements such as 'people with ID are happy' rather than negative ones), neighbours thought both in positive and negative terms about people with ID. Another example of the flexibility of attitudes can be found in the study by Cowan (1999) on neighbours of people with mental illness. She found that neighbours would change their specific thoughts about people with a mental illness, e.g. from vulnerable and in need of protection to dangerous and in need of restriction, to fit the different situations in which

these people could be met. This tells us that there is more to people's attitudes than merely being positive or negative, and that specific thoughts about people with ID can be held simultaneously, and may be associated with different interaction needs, without necessarily being a reflexion of stigmatisation or prejudice.

However, it remains unclear with what intention specific thoughts and beliefs are measured. For example, they are often used to conclude that some neighbours have existing prejudices that would need to be refuted in education, assuming that with correct information about people with ID, neighbours would naturally be positive about interpersonal contact. Moreover, as of yet, knowledge about these specific beliefs is not systematically related to emotions, or further action tendencies beyond opposition or support for a community home.

Psychological mechanisms underlying responses to interpersonal contact with people with ID

In this study we do not set out to measure the existence of global attitudes towards (physical) integration per se, but try to uncover the underlying psychological mechanism responsible for causing specific responses to interpersonal contact with people with ID. This approach means that we take the way in which neighbours respond to people with ID, the various characteristics they ascribe to them, the emotions they cause and the resulting interaction needs, seriously.

Social psychological research into intergroup relations has brought us many insights into how a society makes distinctions between different social groups associated with conditions or behaviours that are perceived as undesirable and how this may motivate certain strategies to prevent or deal with these conditions (Dijker & Koomen, 2007). It is necessary to be able to make distinctions in order to respond appropriately to different conditions, e.g. care for the ill, control those that are dangerous, and protect the vulnerable. Although, of course, societies may differ greatly on what they deem undesirable, e.g. what can be considered illness, dangerousness, or vulnerability. Many attempts have been made to organise social groups in terms of these attributed traits (e.g. Deaux, Reid, Mizrahi & Etheir, 1995; Dijker & Koomen, 2007; Fiske, Cuddy, Glick & Xu, 2002; Frable, 1993; Schmelkin, 1985; Towler & Schneider, 2005; Weiner, Perry & Magnusson, 1988), and it is increasingly understood that these are strongly related to different emotional responses and action tendencies.

Applied to interpersonal contact with people with ID, it seems reasonable that neighbours who see people with ID as vulnerable and harmless would feel more compassion and a tendency to help them than neighbours whose image of people with ID involves unpredictability and annoying behaviour, possibly evoking anxiety or irritation, and a desire to control or limit contact. While the first response would generate more possibilities for social integration (though perhaps involving a particular caring relationship), the second response would not necessarily mean that integration is impossible, but rather that neighbours may have needs that need to be addressed first (e.g. fears that need to be allayed, concerns that need to be heard), before any interpersonal contact with people with ID would be desired by them.

Moreover, it is likely that people with mild ID would evoke vastly different responses in neighbours than people with severe ID. Severity of a condition is often associated with dangerousness, or threat, and people with a severe form of a chronic condition or illness tend to be more socially rejected than those with a mild condition (Crandall & Moriarty, 1995; Deaux et al., 1995). On the other hand, people may not only respond with fear to a severe condition, but may also experience positive emotions such as sympathy or compassion for a person's plight (Bos, Dijker & Koomen, 1999; Dijker & Koomen, 2003). As people with ID moving into neighbourhoods naturally vary in their level of ID, related support needs, and possible disturbing physical appearance or behaviour, it is important to know more about the different emotional responses and interaction needs this may provoke in neighbours. It may be likely that neighbours of people with mild ID may experience less threat and thus be more inclined to not only accept their presence, but also be more willing to interact with them in other neighbourly interactions. Neighbours of people with severe ID may experience more threat, but also more sympathy, making them more ambivalent about social interactions and require, perhaps, more mediation from staff. This difference has largely been ignored, or not systematically studied, apart from one study which has failed to draw conclusions because of a small sample size (Robertson et al., 2005).

Another factor that may influence emotional responses in terms of threat is the size of the group of people with ID moving in. For example, many homes for people with ID are group homes, and quite often, involve more people than one would expect in a single family house (Kozma et al., 2009). From studies on intergroup contact, outgroup size is a factor often associated with experienced threat and social rejection (Hewstone, Rubin & Willis, 2002; Schlueter & Scheepers, 2010). However, studying the influence of facility size so far yielded inconclusive results when relating them to neighbourhood opposition or

support (Jason, Groh, Durocher, Alvarez, Aase & Ferrari, 2008; Pittock & Potts, 1988; Wilmoth et al., 1987). It may be reasonable to assume, however, that a larger facility may in fact be evaluated more negatively by potential neighbours, when specific emotions and interaction needs beyond mere opposition or support are taken into consideration. Specifically, neighbours may experience more threat when a large group of people with ID is moving in (feeling invaded or overrun) and be more concerned with keeping control over their immediate environment by opposing such a group moving in, or be less willing to engage in any continued neighbouring interactions.

Systematic understanding of the emotions aroused by different traits attributions of people with ID can help us understand more about the motivation behind particular neighbourhood responses. We further explore the image of people with ID that neighbours have, and related emotions and interaction needs, in chapters 2 and 3.

Lack of opposition does not equal social integration

Notwithstanding the necessity to overcome opposition from neighbours to the arrival of people with ID into neighbourhoods, one may wonder whether lack of opposition is an indicator of acceptance, of “passive tolerance” (Okolo & Guskina, 1984, p. 49), or suppressed negative attitudes. Statements from neighbours interviewed in two studies may illustrate this: “I see very little of them, they’re no problem” (Pittock & Potts, 1988, p. 37), and “(...) they have proved to be no trouble at all. You don’t know they are there” (Hudson-Allez & Barrett, 1996, p. 11). Moreover, the neighbours interviewed in other studies reported no further contact wishes after an initial open day to get to know the new neighbours (Cook, 1998; McConkey et al., 1993; Overkamp, 2000). This may have researchers wondering whether neighbours may be interested at all in developing a social relationship with people with ID (Cummins & Lau, 2003; Duyvendak & Verplanke, 2010; Myers et al., 1998), and give rise to the question what might be expected from neighbours after people with ID move into a neighbourhood, and whether neighbours can actually be considered contributors to the social networks and well-being of people with ID?

Neighbourhood social integration may not entail more than the tolerance of the presence of people with ID without any further interaction, although whether this is sufficient or desirable could be up for discussion. However, before making any assumptions about the necessary number of ‘coffee visits’ that need to occur between neighbours to speak of social integration, it is important to hear what people find acceptable neighbourly relationships in their particular neighbourhood in the first place. Without a certain baseline of

normal neighbouring, it may be impossible to assess if newly arrived neighbours with ID socially integrate or not. It seems likely that neighbours are more motivated to engage in social contact with people with ID typical of the rather mundane normal neighbouring than to actively stigmatise and exclude them. For a similar situation in other social settings, consider that research into contact between people with and without ID at schools and workplaces, for example, also shows that people actively try to find a balance between what is expected behaviour in that setting, and adapting to the special needs of the person with ID (Chadsey-Rusch, Linneman & Rylance, 1997; Clegg, Murphy, Almack & Harvey, 2008; Novak & Rogan, 2010; Ytterhus & Tossebro, 1999).

However, if people want to engage in different kinds of relationships with their neighbours with ID than with their other neighbours without ID, it is important to understand why their needs are different. Would people with ID be expected to behave according to responsible and reciprocal neighbouring roles which are also expected of other neighbours, or are expectations of them different, perhaps because of their level of ID? Also, while people with ID often live in fairly regular houses not much different from any other private dwelling in a random street, sometimes their residences are rather different; for example, they may live in larger groups, and involve supervisory staff. Do these particular features influence neighbouring interaction at all?

In conclusion, if we accept neighbourhood social integration to mean more than tolerating the presence of people with ID, more needs to be known about the thought processes of neighbours experiencing actual contact with people with ID, and whether their needs and experiences are different from the experiences and needs of people with ID themselves. The experiences of actual interpersonal contact between neighbours with and without ID, and how they may be different or similar, are further explored in chapters 4 and 5.

This thesis

Considering the importance that is attached to social integration of people with ID to improve their quality of life, surprisingly little is known about what kinds of social interaction are exactly desired by the people involved. Clearly, for people with ID, it is necessary that their (potential) neighbours not oppose their arrival in a neighbourhood, but little is known about why they would oppose it in the first place. Secondly, when a home for people with ID in a neighbourhood is established, often there is a sense of disappointment with the lack of interaction with other neighbours, without having a clear picture of what kinds of neighbouring relationships people with and without ID actually want.

In this thesis, applying a social psychological approach, we focus on interpersonal relationships between people with and without ID, distinguishing between anticipating intergroup contact and experiencing actual contact. We study neighbourhood reactions when people with ID are planning to move into a neighbourhood, and the thoughts, emotions and interaction needs of both neighbours with and without ID after such a move, when people meet each other in everyday and mundane social situations.

Before one can be concerned with interpersonal contact and neighbouring relationships between people with ID and their neighbours, understanding the motivations behind positive or negative responses to anticipating contact is necessary. In chapters 2 and 3, using an internet panel survey, we focus on people without ID who reflect on the possible move of people with ID into their neighbourhood. By studying the thoughts and emotions when anticipating contact with people with ID, we tried to find out more about the underlying reasons and motivations for particular relationships with potential neighbours with ID, and conditions prior to them moving in. In **chapter 2**, we explore the image of people with ID that potential neighbours may have and compare this with the image that they may have of other groups often encountering stigma and rejection whilst moving into neighbourhood housing facilities. Using this method, we attempt to uncover the specific thoughts about people with ID that potential neighbours may have. Knowledge about this specific image, perhaps different from the image that other social groups may have, can be used to understand why potential neighbours may refuse contact, or desire particular neighbourly relationships with neighbours with ID different from relationships with members of other social groups, or other neighbours without ID.

Community care policies are not only for people with mild ID, people with severe ID may benefit from, and move into, small scale homes in regular

neighbourhoods too. Additionally, as earlier described, there is a vast difference in group sizes of people with ID moving into neighbourhoods (Kozma et al., 2009). Both these factors, severity of ID and group size, are as of yet not systematically linked to potential neighbours' responses. In **chapter 3**, using the same internet panel as in chapter 2 and focussing on housing facilities for people with ID only, the differences in level of ID and the size of a housing facility in a neighbourhood were related to neighbours' thoughts, emotions and behavioural tendencies. We studied the different responses of potential neighbours to having people with mild ID or severe ID, and a small (4 persons) or large (12 persons) group moving into the property next door.

Public debate and current research focuses regularly on preconceived norms of neighbourhood social integration, often not taking the views of the people concerned into account. In **chapter 4**, rather than talking about people with ID, the actual views and lived experiences of people with ID themselves living in neighbourhoods with other people without ID, are explored. People with mild and moderate levels of ID were invited to talk about their experiences and wishes about daily life in a normal neighbourhood and interacting with neighbours without ID. To complete the picture of experiences of the people concerned, in **chapter 5**, people without ID who are direct neighbours of the people interviewed in chapter 4 were invited to talk about their wishes and experiences. We attempt to generate an overall picture of experiences of the people concerned, identifying barriers and facilitating factors to what they define as desirable neighbouring and social integration.

In **chapter 6**, the results from the studies are summarised and integrated in a theoretically meaningful way to get an overall picture of what goes on in the minds of people when anticipating contact with people with ID in a neighbourhood context, and what people both with and without ID think of actual neighbourly contact with each other.

Finally, in **chapter 7**, the results of this thesis will be discussed in the wider, practical, context of neighbourhood social integration of people with ID. We will reflect on the different insights from the above studies and suggest possible directions for future research concerned with social integration.

Part I

ANTICIPATING INTERPERSONAL
CONTACT WITH NEIGHBOURS WITH
INTELLECTUAL DISABILITY

Chapter 2

Explaining Not-In-My-BackYard Responses to Different Social Groups: The Role of Group Characteristics and Emotions

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Abstract

To examine why people are reluctant to engage in intergroup contact, the present study asked members of a nation-wide online panel ($N = 555$) to imagine that they would get individuals of a particular social group as next door neighbours. Respondents were randomly assigned to one of five different social groups hypothesised to differ in emotion-arousing potential: Elderly people, people with mild or severe intellectual disability, economic refugees, and young offenders. It was found that differences in acceptance between these groups could be well explained by emotions aroused while anticipating contact, yet less well by differences in previous contact with these groups. Furthermore, emotions appeared to be uniquely related to preferred interpersonal relationships. It is concluded that research on how to reduce prejudice through intergroup contact should be complemented with a better understanding of why people are reluctant to engage in such contact in the first place.

Introduction

It is now widely accepted by social psychologists that interpersonal contact between social groups has the potential to reduce prejudice and intergroup conflict. Indeed, this view (also termed the contact hypothesis) has received strong empirical support, as was demonstrated by an impressive meta-analysis of more than 500 studies (Pettigrew & Tropp, 2006). Furthermore, the different conditions under which contact has beneficial effects on intergroup relations are also increasingly understood (for reviews, see Dovidio et al., 2003; Pettigrew, 1998).

Of course, interaction with other group members under optimal conditions can only have beneficial effects on intergroup relations if people do not systematically avoid contact. Unfortunately, we still understand relatively little about the determinants of avoidance of intergroup contact in everyday life. Dixon, Durrheim, and Tredoux (2005) recently observed a “gulf between idealised forms of contact studied by social psychologists and the mundane interactions that characterise most ordinary encounters between groups” (p. 700). These authors also noted that, although contact with other groups may be characterised by some of the optimal conditions identified by social psychologists, segregation and discrimination remain widespread in everyday life. Perhaps, then, research in which intergroup contact traditionally has been treated as an independent variable may have to be complemented with studies focusing on willingness to engage in everyday contact as a dependent variable. The latter focus is closely associated with research on the not-in-my-back-yard or NIMBY phenomenon; i.e. people’s opposition to the siting of certain public service facilities in their neighbourhood (for discussions, see Dear, 1992; Devine-Wright, 2009; Lake, 2001; Zippay, 2007).

The goal of the study reported in this paper was to examine people’s reluctance to engage in contact with members of different social groups under everyday conditions that ought to be highly relevant to participants. In particular, we asked members of the general public to imagine that their current next door neighbours would move and that their place would be taken by four members of a particular social group (e.g. young offenders, people with intellectual disability) who would receive some professional support in daily activities. We expected that differential acceptance of these groups would be influenced by two factors that also have been relatively neglected in research to test the contact hypothesis: The particular characteristics of these groups and the emotions they tend to arouse.

In his theoretical foundation of the contact hypothesis, Allport (1954/1979) recognised the importance of perceived group differences by noting that “it is

conceivable that a given group may have such a preponderance of offensive or dangerous traits that only a saint would consider it unwarranted to avoid and criticize the group" (p. 87). As an example of such a group, he mentioned "ex-convicts" (p. 88). Unfortunately, although it is known that some outgroups profit more from contact interventions than others (see Pettigrew & Tropp, 2006), the influence of perceived group characteristics on intergroup relations has received little systematic theoretical and empirical attention.

With respect to emotions aroused in an intergroup context, it is increasingly documented that different social groups tend to arouse different emotional responses and associated action tendencies, and that these are strongly associated with attitudes toward these groups (e.g. Bos, Dijker & Koomen, 2007; Cottrell & Neuberg, 2005; Dijker, 1987; Fiske et al., 2002). Although emotions are also increasingly measured in research on the effects of intergroup contact (for a review, see Brown & Hewstone, 2005), their role during anticipation and avoidance of contact has remained unaddressed. We expect, however, that unwillingness to engage in intergroup contact is influenced by the kind of emotions aroused by the groups involved, and that these emotions are triggered by people's perception of the undesirable or deviant conditions with which these groups are associated.

Different deviant conditions, different emotional responses

Many attempts have been made to classify perceived deviant conditions in terms of psychologically relevant concepts such as attributed traits, evoked emotional reactions, or relative social rejection (e.g. Deaux et al., 1995; Fiske et al., 2002; Frable, 1993; Schmelkin, 1985; Towler & Schneider, 2005). In a comprehensive review of relevant studies, Dijker and Koomen (2007) concluded that only two dimensions would be necessary and sufficient to explain in a parsimonious and theoretically meaningful way, not only the content but also the emotional implications of the mental representation of deviant conditions.

Specifically, they proposed that the most important distinction people make with respect to deviant conditions is in terms of active-passive deviance, with active deviance referring to threatening conditions that activate a mechanism responsible for the emotions of fear and/or anger (i.e. a fight-or-flight system); and passive deviance referring to conditions that primarily activate a mechanism responsible for feelings of sympathy and pity for needy and dependent others, and motivating care and support. In people's internal representation of deviance, active deviance (e.g. crime, mental illness) and passive deviance (e.g. old age, physical illness) are the opposite poles of a

single dimension because the two underlying mechanisms tend to inhibit each other.

Dijker and Koomen (2007) interpreted the second dimension that people use to classify deviant conditions in terms of the amount of control individuals are thought to exercise over the onset and/or offset of their deviant condition. For example, among the passive deviant conditions, some are associated with lack of controllability (e.g. chronic illness, old age) whereas others imply considerable control or responsibility such as obesity, laziness, or other conditions associated with social parasitism by being dependent and not actively threatening others. Perceived controllability, in turn, influences anger felt at deviant individuals (see Dijker & Koomen, 2003; Weiner et al., 1988). Thus although passive deviance arouses less fear and anger, and more sympathy, than active deviance, controllable forms of passive deviance evoke more intense anger and less sympathy than less controllable ones. Finally, among the active or threatening deviant conditions, perceived controllability also moderates anger responses such that controllable conditions (e.g. intentional crime) arouse more anger than less controllable and more impulsive ones (e.g. particular forms of mental illness). Dijker and Koomen (2007) also recognised that some deviant conditions may have more complex and ambiguous emotional consequences. For example, intellectual disability often implies dependency on others due to lack of intellectual competence (uncontrollable-passive deviance), but may also be associated with threatening behaviour (uncontrollable-active deviance); especially when the disability is explicitly described as serious and involving mental or behavioural problems.

In sum, we propose that the different types of deviance with which different groups tend to be associated are likely to arouse different emotions. Furthermore, this emotion-arousing potential of social groups likely determines people's willingness to engage in intergroup contact.

The present research

In the present study, we assigned respondents to one of five different social groups, each associated with a particular deviant condition, and asked them to what extent they would accept them as next door neighbours, and to report attributed traits, felt emotional reactions, and preferred interpersonal relationships. Criminal behaviour and severe intellectual disability were included as examples of relatively active deviance, whereas old age, mild intellectual disability, and being an economic refugee represented cases of relatively passive deviance. Furthermore, the different conditions included in these categories were intended to vary in perceived controllability. Thus

economic refugees and young offenders were expected to be perceived as having more control over their condition than elderly people and people with mild or severe intellectual disability.

We hypothesised that young offenders would be least, and elderly persons most, accepted as new neighbours, and that economic refugees (due to their high attributed responsibility or perceived social parasitism) would be more rejected than people with mild intellectual disability. We also expected that the latter would be more accepted than individuals with severe intellectual disability.

We also hypothesised that differences in acceptance would in large part be explainable in terms of the different emotions that these groups would arouse. Thus we expected, for example, young offenders to arouse the highest level, and elderly and people with mild intellectual disability, the lowest level of fear and anger; the reverse pattern was expected for feelings of sympathy. Importantly, we hypothesised that differences in acceptance between social groups would be removed after controlling for differences in aroused emotions. In contrast, we expected that differences in previous contact with these different groups would be less able to explain differences in acceptance; a result which would suggest that in anticipating contact as neighbours, emotion-arousing potential would be more important in explaining willingness to engage in close contact than frequency of previous encounters.

Finally, we hypothesised that emotions experienced while anticipating intergroup contact would be meaningfully related to measures reflecting action tendencies and goals relevant to neighbouring (for general views on the relation between emotions and behavioural tendencies, see Frijda, 1986; Roseman, Wiest & Swartz, 1994). For example, we hypothesised that people responding with anxiety and anger to the anticipated arrival of a deviant group would prefer a hierarchical relationship with their new neighbours (with respondents playing the dominant role) and would appreciate a prior opportunity to vote against their arrival. In contrast, those who would feel sympathy should report greater willingness to engage in a caring or reciprocal relationship, and to show more interest in different kinds of information about the particular group.

Method

Design and participants

Participants were members of an online internet panel representative for the Dutch population (for a methodological discussion of using online panels, see

Göritz, 2007). Stratifying on gender, age, educational level, and province, 850 participants were randomly assigned to five conditions of an experimental design, each involving a different target group. The final sample consisted of 555 respondents (response rate = 65%) and was evenly distributed over the five conditions; elderly persons ($n = 116$), people with mild intellectual disability ($n = 104$), people with severe intellectual disability ($n = 110$), economic refugees ($n = 116$), and young offenders ($n = 109$). Importantly, these five conditions appeared to be equivalent with respect to gender, $\chi^2(4, N = 555) = 7.95, p = .09$, age, $F(4, 550) = 1.42, p = .23$, education, $\chi^2(8, N = 555) = 14.72, p = .07$, and income, $\chi^2(8, N = 423) = 7.16, p = .52$.

The sample included 276 men and 279 women. The average age was 48.23 years ($SD = 15.88$); 35.3 % had a low, 40.7 % a medium, and 24.0 % a high level of education. Furthermore, 20.2 % had a below-average, 26.1 % an average, and 29.9 % an above-average income. Similar distributions of demographic variables are found in the Dutch population (Centraal Bureau voor de Statistiek, 2008). Moreover, there were no differences between respondents and the none-response group with respect to demographic characteristics, except for age, $F(1, 849) = 25.11, p < .01$. The non-response group appeared to be somewhat younger ($M = 42.53, SD = 15.80$) than the response group ($M = 48.23, SD = 15.88$).

Procedure

Members of the panel were required to log on to the internet site of the online research company and to fill out a questionnaire, ostensibly asking questions about neighbouring in general. Participants could answer the questions in their own tempo but were prevented to return to previous questions. The questionnaire took about 25 minutes to complete. Completion was rewarded with points that could be exchanged for discount coupons or gift certificates.

The first part of the questionnaire contained questions about preferred interpersonal relationships in the context of neighbouring in general, which would later be repeated for the specific social group to which the respondent was assigned. In this way, we expected to ensure that respondents would think thoroughly about their own current living conditions, and to differentiate their responses to the specific group from their responses to neighbours in general. After the general questions, the particular social group was introduced as follows:

People who used to live in special institutions are increasingly moving into normal neighbourhoods. For example, the

government is currently looking for suitable locations to house [members of group X] in your neighbourhood. Imagine that your current next door neighbours would move and that the community council has decided to let [four members of group X] take their place. If necessary, the house will be adapted to these new inhabitants. Although [members of groups X] live independently, they will occasionally receive professional assistance.

To ensure that participants would distinguish the social groups in a uniform manner we provided some additional information about the groups. In particular, we explicitly mentioned that the elderly did not suffer from mental problems; that the level of intelligence of the groups with mild and severe intellectual disability was comparable to that of an eleven-year old or two-year old, respectively, yet that the former group did not suffer from physical problems, whereas the latter was associated with both physical and behavioural problems; that the refugees wanted to live in the Netherlands to escape from poverty and hence for economic reasons and received a financial allowance and professional guidance; and that the young offenders previously had completed sentences for different offenses. We choose to fix group size at four members to represent the size of a regular household.

Measures

Acceptance

Respondents rated the extent to which they found it acceptable to get members of the particular social group as new next door neighbours on a 5-point scale running from *very unacceptable* to *very acceptable*.

Attributed traits

Respondents rated on 5-point scales to what extent they attributed different traits to members of the particular social group. On the basis of theoretical and empirical reasons, we composed scales reflecting attributed sociability (with individual traits *friendly*, *outgoing*, *take advantage of others*, *anti-social*, and *bossy*, with the last three items reverse coded; Cronbach's $\alpha = .82$); dangerousness (*dangerous*, *unpredictable*, and *self-controlled*, with the last item reverse coded; $\alpha = .68$); and vulnerability (*vulnerable* and *dependent on others*, $r = .46$, $p < .01$).

Emotions

Respondents reported the intensity of experienced emotions while imagining to receive members of the deviant group as new neighbours, on a scale running from 1 = *not at all* to 5 = *very strong*. The following four scales were formed: Sympathy (*compassion, tenderness, and sympathy*; $\alpha = .83$), anxiety (*worry, insecurity, and fear*; $\alpha = .69$), anger (*irritation and anger*; $r = .67, p < .01$), and disrespect (*contempt and disgust*; $r = .70, p < .01$). Because the latter two scales are highly correlated ($r = .71, p < .01$) and results for the two appeared highly similar, we will only report analyses performed on the anger scale.

Previous contact

Respondents were asked to estimate the frequency of previous contact with members of the social group on scales running from 1 = *never* to 5 = *very regular*, separately for merely seeing them, having a chat, and visiting.

Preferred relationships and preparation

Respondents were asked to use scales running from 1 = *very undesirable* to 5 = *very desirable* to indicate how much they preferred different kinds of interpersonal relationships with their new neighbours. We distinguished between a relationship with minimal or only superficial contact (correlation between the two was $r = .35, p < .01$); a reciprocal one in which neighbours would exchange small favours; one in which the respondent would be ready to provide (long-term) care to the next door neighbours; a hierarchical relationship in which the neighbours would play a dominant and controlling role (e.g. by requiring respondents to adapt to certain wishes with respect to the timing of parties); and a hierarchical relationship in which the respondent would play the dominant and controlling role.

Using the same 5-point answering scale, respondents also indicated their need for education and support prior to the move in terms of an “open house” (to get acquainted with the house and its inhabitants), general information about the social group, opportunity for deciding which members of the group should be selected to move in, and finally, opportunity for voting for or against the arrival of the social group.

Results

Acceptance

An analysis of variance (ANOVA) on the acceptance of the prospective neighbours, with social group as an independent variable, revealed a main effect of this variable, $F(4, 550) = 38.72, p < .001, \eta^2 = .22$. As shown in Figure 2.1a, and confirmed by post-hoc analyses, young offenders were least, and elderly persons and people with mild intellectual disability, most accepted as new next door neighbours. Also consistent with our hypothesis, while economic refugees were less accepted as neighbours than elderly or intellectually disabled people, they were met with greater acceptance than young offenders. Furthermore, people with severe intellectual disability were met with less acceptance than those with mild intellectual disability.

Attributed traits

A multivariate analysis of variance (MANOVA) on all attributed traits and emotions, with social group as an independent variable, resulted in a multivariate main effect of this variable, $F(24, 2192) = 20.74, p < .001$, partial $\eta^2 = .19$. We first discuss the results of the univariate ANOVAs on attributed traits.

These ANOVAs revealed main effects of social group on sociability, $F(4, 550) = 80.18, p < .001, \eta^2 = .37$, vulnerability, $F(4, 550) = 23.53, p < .001, \eta^2 = .15$, and dangerousness, $F(4, 550) = 38.50, p < .001, \eta^2 = .30$. Consistent with the dimensional analysis presented above, young offenders were seen as most, and elderly people as least, dangerous, and are apparently associated with active and passive deviance, respectively (see Figure 2.1b). People with mild or severe intellectual disability and economic refugees occupy a middle position on this trait and were perceived as almost equally dangerous. Post hoc analysis of the means for attributed dangerousness indicated, however, that all three groups were seen as significantly more dangerous than elderly people but less dangerous than young offenders. Elderly persons and people with mild or severe intellectual disability all were seen as equally and relatively high in perceived sociability and vulnerability (post hoc tests did not reveal differences among the means), and more so than economic refugees and young offenders. Interestingly, however, economic refugees were not only seen as less threatening, but also as more sociable than young offenders.

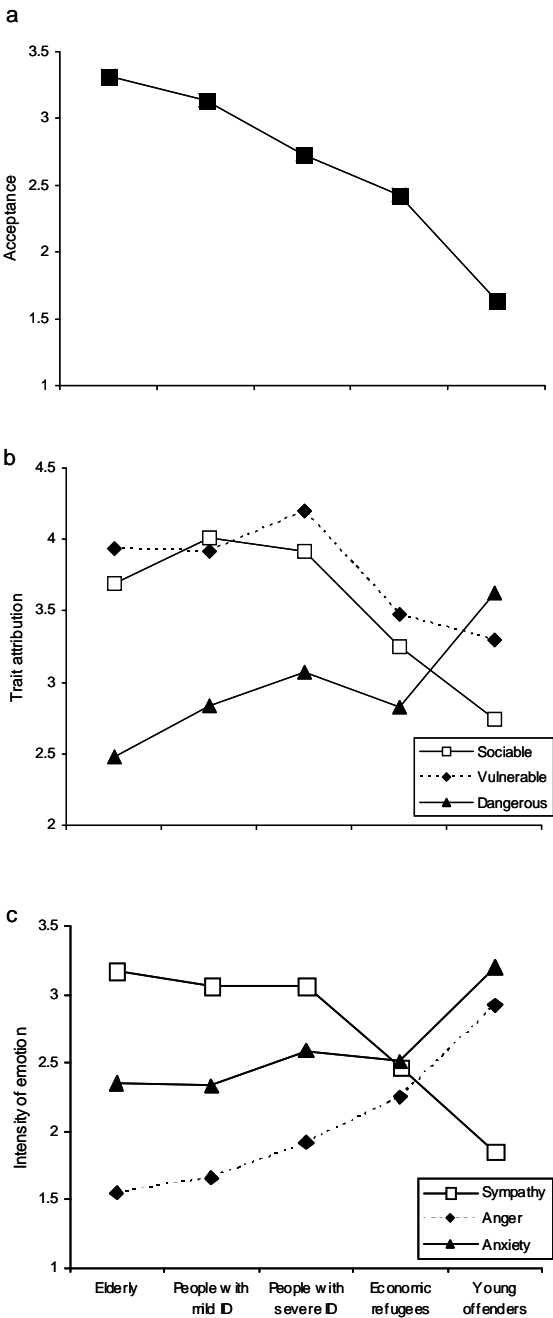


Figure 2.1 Acceptance, attributed traits, and emotions as a function of social group (ID = intellectual disability).

Emotions

Similar ANOVAs performed on reported emotions yielded main effects of social group on sympathy, $F(4, 550) = 52.52, p < .001, \eta^2 = .28$, anxiety, $F(4, 550) = 18.72, p < .001, \eta^2 = .12$, and anger, $F(4, 550) = 38.43, p < .001, \eta^2 = .22$. As can be seen from Figure 1c, the pattern of anxiety largely follows the pattern of perceived dangerousness, confirming once more that respondents distinguished our selected deviant conditions in terms of active vs. passive deviance. Note, however, that only the mean for young offenders differs significantly from the other means. A similar correspondence between profiles of attributed traits and emotions is found between, on the one hand, sociability and vulnerability, and on the other hand, sympathy and anger. Thus elderly and mild or severe intellectually disabled people not only are perceived as relatively social and vulnerable but also are associated with relatively strong sympathy and weak anger. Post hoc tests revealed no significant differences between the three groups, except between elderly and severe intellectual disability in terms of anger. Furthermore, the differences between these three groups and economic refugees and young offenders were significant. An ambivalent way of responding to people with severe intellectual disability, however, is suggested by greater anxiety and anger, despite relatively high sympathy. Finally, the relatively passive nature of economic refugees is once more suggested by the finding that they arouse both significantly more sympathy and less anger than young offenders.

Explaining acceptance in terms of previous contact and emotion-evoking potential

Figure 2.2 displays the means for reported previous contact with the different social groups. As can be seen, the patterns of means parallels the pattern obtained for acceptance; for seeing around, $F(4, 550) = 20.94, p < .001, \eta^2 = .13$, talking to, $F(4, 550) = 17.82, p < .001, \eta^2 = .11$, and visiting, $F(4, 550) = 14.95, p < .001, \eta^2 = .10$. This raises the question if differential acceptance can be explained in terms of differences in previous contact. When we conducted an analysis of covariance, we found that inclusion of the three contact measures as covariates did not remove the significant effect of social group on acceptance reported above; new $F(4, 547) = 27.02, p < .001, \eta^2 = .16$. This analysis also revealed that only one contact measure (*talk to*) had a general influence on acceptance, $F(4, 547) = 5.85, p < .05, \eta^2 = .01, \beta = .15$. However, after entering the emotions as covariates, we were able to completely remove the effect of social group on acceptance; new $F(4, 547) = 2.20, p > .05, \eta^2 = .02$. Note that the

individual emotions strongly predicted acceptance; for sympathy, $\beta = .42$, for anger, $\beta = -.46$, and for anxiety, $\beta = -.29$. To examine to what extent previous contact moderated the influence of emotions on acceptance, we summated the three contact measures, multiplied the result with each of the three emotions, and added the three products to the covariance equation. As all three F values were nonsignificant, $ps > .30$, we conclude that moderation was absent. Although entering the attributed traits instead of emotions as covariates resulted in a similarly large reduction of the effect of social group on acceptance, its effect remained significant; new $F(4, 547) = 6.79, p < .001, \eta^2 = .05$.

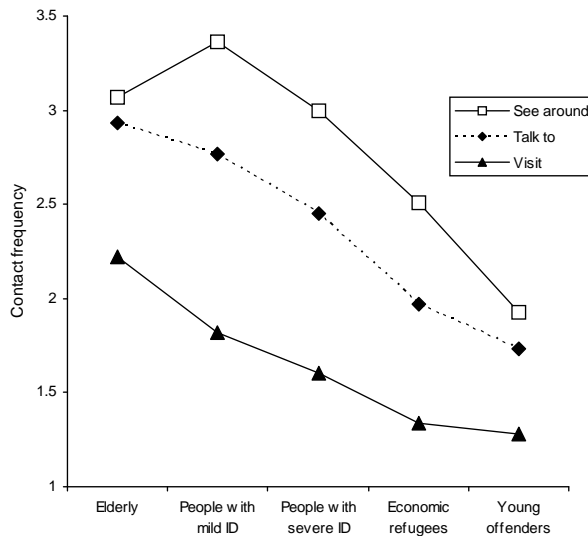


Figure 2.2 Frequency of previous contact with social groups (ID = intellectual disability).

Behavioural implications of different emotions

Assuming that emotions are linked to different action tendencies or interaction goals (cf. Frijda, 1986), we expected that different emotions would have different implications for the kind of interpersonal relationships with deviant groups that people would prefer in the context of neighbouring, as well as for the way in which they desired to prepare for their arrival. Table 2.1 indeed suggests that this is the case. Specifically, the more anxiety is experienced while

anticipating contact with deviant groups, the more respondents preferred a prior opportunity to vote against the arrival of these groups or to have a voice in determining which specific individuals should move in next door. Anxiety also positively affects the preference for engaging in hierarchical relationships with deviant groups, with respondents playing a dominant role, and reduces willingness to engage in a reciprocal relationship. Aroused anger has similar behavioural consequences, yet it also reduces the felt need for an open house and for a caring relationship, and increases the desire for minimal or superficial contact. Finally, sympathy appears to have primarily pro-social implications, as it is positively correlated with a felt need for both a caring and reciprocal relationship. Those high in sympathy also tend to express more interest in an open house and receiving information about the groups (note that anxiety is also positively associated with a desire for more information, but not with an open house; perhaps, because the latter may also involve contact with the new inhabitants). Interestingly, unlike respondents who experience strong anxiety, those who report strong sympathy are also willing to engage in a hierarchical relationship in which the other group is allowed to play a more controlling and dominant role.

Table 2.1 Pearson correlations between emotions and preferred relationships and preparation

	Sympathy	Emotion Anger	Anxiety
Preferred relationship			
Minimal or superficial contact	-.24**	.14**	.03
Reciprocity	.38**	-.33**	-.12**
Extensive care	.40**	-.19**	-.05
Social group controls	.17**	-.05	.02
Respondent controls	.01	.13**	.16**
Preferred preparation			
Open house	.23**	-.23**	.01
Information	.15**	-.02	.14**
Influence on who moves in	-.03	.22**	.24**
Anonymous vote	-.18**	.41**	.30**

Significance is indicated as follows: ** $p < .01$.

Discussion

To complement research on the effects of intergroup contact on prejudice reduction (for reviews, see Dovidio et al., 2003; Pettigrew, 1998; Pettigrew &

Tropp, 2006), the present study inquired about people's responses to other groups while anticipating to interact with them in highly relevant everyday situations. In particular, we were concerned about people's tendency to avoid intergroup contact in the context of neighbouring and its relation with group differences and aroused emotions.

The present findings indicate that type of deviance with which a social group is associated exerts an important influence on the degree to which members of this group are rejected as neighbours, and that this influence is accounted for by the emotions that are typically aroused by type of deviance. Importantly, the emotion-evoking potential of the studied social groups exerted a much stronger influence on willingness to engage in future contact than frequency of previous contact with these groups. Apparently, even people who report a high frequency of previous intergroup contact may base their decisions to engage in future contact on emotions typically aroused by the particular group involved. Because we employed hypothetical situations, it would be desirable for future research to repeat the present study under conditions in which participants will be actually confronted with the location of service or housing facilities in their neighbourhood. Under these circumstances, it may also be useful to employ a longitudinal research design to examine the relationship between emotions and desires reported during anticipation and actual contact.

Research on the effects of intergroup contact may have to take into account that certain groups arouse so strong reluctance to engage in contact, that interventions, even if they are optimal according to the contact hypothesis, may have limited reach (see also Dixon et al., 2005). Knowing the particular emotional and motivational correlates of avoidance of contact may help to explain why and to overcome resistance in seeking contact. The present study suggests, for example, that people who are anxious about the arrival of deviant groups may not only want to prevent their arrival through voting but may also desire to be informed and to engage in certain kinds of relationships in which safety can be guaranteed by means of interpersonal control. While the first preference clearly represents an undesirable outcome for policy makers, the latter two preferences should alert them to the possibility that for anxious people, contact could be satisfactory under certain conditions (for an application of this idea to interpersonal contact with persons with AIDS, see Dijkster, Koomen & Kok, 1997). Unfortunately, the behavioural correlates of anger found in this study (unwillingness to engage in any contact, no desire for information or an open house) suggest rather different interventions for people who primarily experience anger. By contrast, when sympathy is aroused

during anticipation of intergroup contact, the prospects of realising satisfactory relations with neighbours through caring or reciprocal relationships seem rather good.

Our findings and theoretical interpretations also suggest that the NIMBY phenomenon may be more complex than assumed by policy makers concerned with neighbourhood reactions to the siting of service or housing facilities for purposes of rehabilitation and social integration of special groups. In particular, these reactions often are interpreted in a dichotomous manner; as either against (in which case one tends to speak of NIMBY) or in favour of the placement of these facilities in one's neighbourhood. Unfortunately, such a view obscures the different emotions and associated needs experienced while anticipating contact, and hence may miss opportunities to help create conditions of contact that satisfy the different needs of the groups involved. Equally important, such a view may mistake the disappearance of explicit opposition once new neighbours have settled for normal neighbouring or successful social integration of the special groups involved. Yet, the decline of explicit opposition after introduction of certain human service facilities may also imply that negative emotions are suppressed and contact is still avoided whenever possible (e.g. Cowan, 1999; Van Alphen, Dijker, Borne & Curfs, 2010).

To conclude, our research has shown in different ways that it is fruitful to complement research on the effects of intergroup contact with a better understanding of people's expectancies, emotions, and desires while they anticipate contact with different social groups (cf. Dixon et al., 2005).

Chapter 3

The Influence of Group Size and Severity of a Stigmatising Condition on Social Acceptance: The Case of People with Intellectual Disability moving into Neighbourhoods

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Abstract

Dutch adults from a nation-wide internet panel ($N = 426$) were asked to imagine that their next door neighbours would move out and that people with intellectual disability would move in. Severity of disability and group size were varied to manipulate intergroup threat. These two factors independently influenced social acceptance and a variety of emotional and behavioural measures. In particular, it was found that a large group with severe disability aroused the strongest, and a small group with mild disability the weakest, negative responses. Small groups with a severe disability and large groups with a mild disability aroused similar and intermediate negative responses. Results are discussed in terms of theories of intergroup threat and stigmatisation. Practical implications for predicting the success of deinstitutionalisation and social integration of groups with special needs are addressed.

Introduction

Imagine that your next door neighbours move out and that it is announced that their place will be taken by members of a particular social group that you experience as threatening. How would you initially react to such an announcement? Would you respond with anxiety, irritation, and motivation to prevent them from moving in (e.g. by filing complaints with authorities) or engage in preparatory behaviours that could reduce the experienced threat (e.g. ask for additional information, visit an “open house”)? Or would other perceived traits of the particular group (e.g. are they in need of help and sympathy?) determine your initial reactions? And to what extent would your emotional and behavioural responses towards these new neighbours be determined by their number or threatening nature of their condition?

Answering these kinds of questions seems relevant for predicting the effects and success of current attempts to let members of special groups such as people with mental illnesses or disabilities live in small-scale facilities in regular neighbourhoods for purposes of, what has been variously termed, deinstitutionalisation, social integration, or rehabilitation (Beltman, 2001; Mansell & Beadle-Brown, 2009a). (For an attempt to measure and compare deinstitutionalisation efforts for people with intellectual disability (ID), the focus of our study, in European countries, see Mansell et al., 2007). Unfortunately, in the literature on social integration of special groups, processes at the interpersonal level are seldom addressed in detail. Instead, social responses of neighbourhoods to the siting of small-scale living and care facilities tend to be conceived in a dichotomous manner: Either involving general acceptance or opposition, with the latter sometimes associated with irrational prejudice or not-in-my-backyard responses (Cowan, 2003; Currie, Trute, Teft & Segall, 1989; Dear, Takahashi & Wilton, 1996; Graham & Hogan, 1990; Jason et al., 2008). These not-in-my-backyard responses tend to be explained in terms of different demographic variables, amongst others, home ownership, social economic status, or having children (Dear et al., 1996; Graham & Hogan, 1990; Schwartz & Rabinovitz, 2001). This approach to neighbourhood reactions, however, tells us little about the psychological mechanisms operating at the interpersonal level and likely determining the quality of contact with members of special groups.

Unfortunately, social-psychological research does not readily suggest how neighbourhood reactions to the siting of facilities for special groups should be conceptualised at the interpersonal level either. Traditionally, there has been a strong emphasis on intergroup relations and biases in perception and evaluations, and the influence of social categorisation, minority and majority

status, and concerns with group identity (for a review, see Hewstone et al., 2002; Yzerbyt & Demoulin, 2010). Such an intergroup perspective also figures prominently in understanding how contact between members of different social groups may help to reduce prejudice and foster harmonious relationships. Fortunately, researchers increasingly emphasise the importance of measuring specific emotions that may mediate the effects of contact on intergroup attitudes (Brown & Hewstone, 2005); emotions that, in principle, may also play a causal role during interpersonal encounters.

In this paper we hope to contribute to revealing the psychological mechanisms that are involved in responding to social integration of special groups, focusing specifically on people with intellectual disability (ID). We measured a wide variety of emotional and behavioural responses, and experimentally manipulated two factors thought to be especially relevant in influencing these reactions: Group size and severity of a stigmatising condition. Before presenting the study we consider what is special about people with ID as neighbours, and how both group size and level of ID may influence different emotional and behavioural reactions to them.

What is special about having people with intellectual disability as neighbours?

In-depth interviews with neighbours of care and living facilities for people with ID suggest that neighbours' reactions are determined by both the characteristics of the residents of these facilities and the particular behaviour of supporting staff (Van Alphen et al., 2010). For example, in reporting on perceived differences with neighbouring with other, non-handicapped neighbours, respondents mentioned that their neighbours with ID may display disturbing behaviour or produce strange noises, as well as show certain vulnerabilities that arouse care, and sociable traits that are experienced as pleasant. These perceptions are confirmed by quantitative studies. For example, compared to faces of non-handicapped individuals, faces of persons with ID arouse a mixture of fear and sympathy (Dijker, de Vries & ter Haar, 1998; Dijker, Tacken & van den Borne, 2000), with fear gaining in importance as facial deviance and severity of handicap increases.

In addition, the behaviour of supporting staff figures significantly in neighbours' perceptions. For example, instead of engaging in direct interpersonal relationships with the residents, neighbours may approach staff or vice versa in case of experienced problems. Staff may also feel a need to educate the neighbourhood about the care facility and its residents and organise an "open house". Unfortunately, as van Alphen et al. (2010) found,

staff may violate normal principles of neighbouring by behaving in atypical ways (e.g. by not introducing themselves, failing to greet neighbours, or obtrusive mediation of contact between residents and neighbours).

Furthermore, and in a more positive sense, relationships between neighbours with and without ID may be unusual in that the non-handicapped neighbours sometimes tended to adopt the role of “volunteer”, thus entering into an asymmetrical relationship in which services and support are provided to a handicapped individual but not vice versa (Van Alphen et al., 2010).

Severity of disability

Several attempts have been made to distinguish deviant conditions or stigmas in terms of a limited number of underlying dimensions (e.g. Fiske et al., 2002; Jones, Farina, Hastorf, Markus, Miller & Scott, 1984). Although there are important differences between the different proposals (for a review, see Dijker & Koomen, 2007), one dimension that is repeatedly proposed is severity, which is often associated with dangerousness or threatening character (Crandall & Moriarty, 1995; Deaux et al., 1995; Dijker & Koomen, 2007; Jones et al., 1984). However, as Dijker and Koomen (2003) and Bos, Dijker and Koomen (1999) have shown, severity of a chronic illness is not only related to threat and fear, but also to perceived need and hence with compassion and pity. With respect to ID, it may be possible that a severe level of ID may be associated with stronger anxiety and perceived vulnerability. However, whether people with a severe ID also evoke stronger positive emotions such as sympathy than people with mild ID remains unclear, especially in a realistic intergroup setting.

Group size

Group size has been accorded an important role in the intergroup literature in that it would be causally responsible for experienced threat which, in turn, would fuel hostile reactions to other groups (Blalock, 1967; Hewstone et al., 2002; Schlueter & Scheepers, 2010; Stephan & Stephan, 1985). With a few exceptions, however, both group size and threat have been rather broadly conceived. For example, size has been measured in terms of proportion of outgroup members living in a particular neighbourhood (Schlueter & Scheepers, 2010), and threat in terms of expected loss of own group or cultural identity, competition over scarce resources (e.g. with respect to housing or labour), and even jealous reactions to affirmative actions favouring minority groups. Interestingly, group size also is related to prejudice reduction as it may

increase opportunities for interpersonal contact (Allport, 1954/1979; Schlueter & Scheepers, 2010).

In contrast to broad conceptions of threat, Stephan and Stephan's (1985) concept of intergroup anxiety draws attention to the possibility that threat may also be associated with the perception of specific dangerous features of outgroup members during face-to-face contact (see also Devine, Evett & Vasquez-Suson, 1996). Indeed, with respect to people with ID, there is much reason to believe that perceived danger and threat are associated with concrete physical appearances and behaviours that remain visible during interpersonal contact, rather than with issues such as economic competition or loss of social identity. Furthermore, it seems reasonable to expect that a simple increase in the number of threatening individuals in one's environment will intensify perceived threat and feelings of anxiety as this may imply less opportunity for avoidance and lower perceived control (e.g. one may feel "surrounded" or "trapped" by persons one perceives as threatening). There is less reason to believe that during anticipation of contact, an increase in the number of expected next door neighbours with ID will promote social acceptance, unless one assumes that this increase would go together with an increase in the number of spontaneously imagined satisfactory encounters.

Group size has to our knowledge never been manipulated in terms of concrete and perceptible changes in the number of individual group members that will be encountered as next door neighbours. We will ask ourselves, for example, if it matters whether people expect to get twelve instead of four new neighbours with ID

The present research

In the present study, we asked members of the general public to imagine that people with ID would move into their neighbourhood. We measured their acceptance of the new situation, as well as traits attributed to the new neighbours, emotional reactions, expected neighbouring behaviour, and preferred preparation for their arrival. Group size and severity of ID were independently manipulated, each at two levels. We hypothesised main and additive effects of these factors. In particular, we expected that larger size and more severe disability would result in less acceptance, more negative trait attributions and emotions, as well as more behaviour (e.g. solving problems with staff rather than residents) and stronger preferences for preparation (e.g. prior selection of residents, organisation of an "open house") that could reflect greater threat and anxiety. In addition, we predicted the four cell means of this design to show a specific pattern on these variables. In particular, consistent

with the expected additive effects, we predicted a large difference in responses to a small group of individuals with mild ID and to a large group of individuals with severe ID. However, we expected no differences in responses to the two other combinations of group size and severity (small group – severe ID, large group – mild ID) as both combinations may weaken the fear-arousing aspects of one of the two features.

Method

Participants and design

Participants were members of an online internet panel representative of the Dutch population. This panel consists of members of the general public who are regularly invited to participate in online survey research on a wide variety of topics, receiving as rewards points that could be exchanged for discount coupons or gift certificates. Stratifying on gender, age, educational level, and province, 680 participants were randomly assigned to a 2 (severity: mild vs. severe intellectual disability) \times 2 (group size: 4 vs. 12 group members) experimental design. The final sample consisted of 426 respondents (response rate = 63 %) which was evenly distributed over the four cells design (cell *N*s ranged from 104 to 110). Importantly, the four conditions appeared to be equivalent with respect to gender, $\chi^2(3, N = 426) = 2.23, p = .53$, age, $F(3, 422) = 1.16, p = .32$, and income, $\chi^2(6, N = 315) = 8.35, p = .21$. The four conditions seemed to differ somewhat with respect to level of education, $\chi^2(6, N = 426) = 12.97, p = .04$, with the “mild – small group” cell consisting of a relatively small proportion of respondents with a high level, and relatively large proportion of respondents with a medium or low level of education.

The sample consisted of 217 men and 209 women. The average age was 48.60 years ($SD = 15.67$); 33.8 % had a low, 43.0 % a medium, and 23.2 % a high level of education. Furthermore, 18.3 % had a below-average (< €23,000), 23.2 % an average (> €23,000, < €34,000), and 32.4 % an above-average income (> €34,000). Similar distributions of demographic variables are found in the Dutch population (Centraal Bureau voor de Statistiek, 2008). Moreover, there were no differences between respondents and those who failed to participate or complete the questionnaire in terms of demographic characteristics, except for age, $F(1, 678) = 14.77, p < .01$. The non-response group appeared to be somewhat younger ($M = 43.79, SD = 16.01$) than the response group ($M = 48.60, SD = 15.66$).

Procedure

Members of the panel were required to log on to the internet site of the online research company and to fill out a questionnaire, ostensibly asking questions about neighbouring in general. Participants could answer the questions in their own tempo but were prevented to return to previous questions. The questionnaire took about 25 minutes to complete.

The first part of the questionnaire contained questions about preferred interpersonal relationships in the context of neighbouring in general. In this way, we hoped to ensure that respondents would think thoroughly about their own current living conditions, and to differentiate their responses to potential neighbours with ID from their responses to neighbours in general. After the general questions, the new neighbours with ID were introduced as follows:

People who used to live in special institutions are increasingly moving into normal neighbourhoods. For example, the government is currently looking for suitable locations to house people with ID in your neighbourhood. Imagine that your current next door neighbours would move and that the community council has decided to let [four/twelve] people with [mild/severe] ID take their place. If necessary, the house will be adapted to these new inhabitants. Although these people with ID live independently, they will occasionally receive professional assistance.

To ensure that participants would distinguish between the people with mild or severe ID in a relatively uniform manner we provided some additional information. In particular, we explicitly stated that the level of intelligence of the people with mild and severe intellectual disability was comparable to that of an eleven-year old or two-year old, respectively, yet that the former group did not suffer from physical problems, whereas the latter was associated with both physical and behavioural problems. In addition, we varied group size to represent either the size of a regular household (four persons), or a small institution (twelve persons).

Dependent variables

Acceptance

Respondents rated the extent to which they found it acceptable to get people with ID as new next door neighbours on a 5-point scale running from *very unacceptable* to *very acceptable*.

Attributed traits

Respondents rated on 5-point scales (1 = *totally disagree*, 5 = *totally agree*) to what extent they attributed different traits to their new neighbours. On the basis of theoretical and empirical reasons, we composed scales reflecting attributed sociability (with individual traits *friendly*, *outgoing*, *take advantage of others*, *anti-social*, and *bossy*, with the last three items reverse coded; Cronbach's $\alpha = .69$); unpredictability (*unpredictable*, and *self-controlled*, with the last item reverse coded, $r = .39$, $p < .01$); and vulnerability (*vulnerable* and *dependent on others*, $r = .45$, $p < .01$). Perceived dangerousness was measured with a single item. (The correlation between perceived unpredictability and dangerousness was, $r = .40$, $p < .001$.)

Emotions

Respondents reported the intensity of experienced emotions while imagining to receive people with ID as new neighbours, on answering scales running from 1 = *not at all* to 5 = *very strong*. The following four scales were formed: Sympathy (*compassion*, *tenderness*, and *sympathy*; $\alpha = .73$), anxiety (*worry*, *insecurity* and *fear*; $\alpha = .70$), and anger (*irritation* and *anger*; $r = .58$, $p < .01$).

Preferred preparation

Using a 5-point answering scale (1 = *very undesirable*, 5 = *very desirable*), respondents indicated the felt need for education and support prior to new neighbours moving in, in terms of an "open house" (to get acquainted with the house and its inhabitants), opportunity for influence (e.g. in deciding which individuals with ID should be selected to move in), and absence of any preparation.

Neighbouring behaviours

Respondents indicated on two 5-point scales (1 = *very undesirable*, 5 = *very desirable*) the degree to which they preferred to solve problems related to

neighbouring with staff or residents with ID, respectively. Respondents were also presented with a vignette describing them spending time on a regular basis as a volunteer for one of their next door neighbours with ID. They indicated using a 5-point scale (1 = *very negatively*, 5 = *very positively*) the degree to which they respond positively or negatively to such a relationship.

Previous contact

Respondents were asked to estimate the frequency of previous contact with people with ID (either mild or moderate, depending on study condition) on scales running from 1 = *never* to 5 = *very regular*. Separate measures were included for seeing, talking to, and visiting people with ID. In testing our hypothesis, we used these measures as covariates.

Results

A 2 (severity) \times 2 (size) multivariate analysis of variance (MANOVA) on all dependent measures, with contact measures included as covariates, resulted in a multivariate main effect of severity, $F(14, 406) = 2.73$, $p < .001$, $\eta^2 = .09$, and group size, $F(14, 406) = 2.44$, $p < .01$, $\eta^2 = .08$. No multivariate interaction effect was found. We next discuss the results of the univariate ANOVAs.

Acceptance

The ANOVA on acceptance revealed a main effect of severity, $F(1, 419) = 4.52$, $p < .05$, $\eta^2 = .01$. People with mild ID were considered more acceptable as neighbours ($M = 3.16$, $SD = 1.20$) than people with severe ID ($M = 2.84$, $SD = 1.23$). Group size also had a significant effect, $F(1, 419) = 5.64$, $p < .05$, $\eta^2 = .01$. Respondents found a smaller group more acceptable ($M = 3.14$, $SD = 1.17$) than a larger group ($M = 2.85$, $SD = 1.24$). No interaction turned up between severity and group size (see Table 3.1 for details).

Attributed traits

Similar ANOVAs revealed main effects of severity on vulnerability, $F(1, 419) = 22.08$, $p < .001$, $\eta^2 = .05$, and unpredictability, $F(1, 419) = 17.05$, $p < .001$, $\eta^2 = .04$. Neighbours with a severe level of ID were seen as more vulnerable, ($M = 4.22$, $SD = .72$) than neighbours with mild ID ($M = 3.87$, $SD = .78$); the former were also seen as more unpredictable ($M = 3.64$, $SD = .81$) than the latter ($M = 3.32$, $SD = .76$). No effects on sociability and dangerousness were found. Group size did not affect these trait attributions; a finding that can be explained by

assuming that traits are stereotypically associated with group membership rather than group size.

Emotions

Similar ANOVAs revealed a main effect of severity on experienced anger, $F(1, 419) = 5.31, p < .05, \eta^2 = .01$, and anxiety, $F(1, 419) = 4.82, p < .05, \eta^2 = .01$. People with severe ID evoked more anger ($M = 1.99, SD = .94$) than those with mild ID ($M = 1.77, SD = .86$) and also more anxiety ($M = 2.58, SD = .88$) than neighbours with mild ID ($M = 2.37, SD = .85$). Group size had a main effect on reported anger, $F(1, 419) = 3.93, p < .05, \eta^2 = .01$, and sympathy, $F(1, 419) = 4.31, p < .05, \eta^2 = .01$. A larger group of people with ID evoked more anger ($M = 1.97, SD = .94$) than a smaller group ($M = 1.80, SD = .87$). Moreover, respondents experienced more sympathy for smaller groups ($M = 3.07, SD = .78$) than for larger groups ($M = 2.92, SD = .86$). We did not find a main effect of size on anxiety.

Preferred preparation

Group size had a marginal main effect on respondents' wish for an "open house", $F(1, 419) = 3.02, p < .10, \eta^2 = .01$. An "open house" was seen as more desirable in the case of a large ($M = 4.17, SD = .99$) than small group moving in ($M = 4.01, SD = 1.04$). Respondents also found the absence of any preparation less desirable in responding to a large ($M = 1.49, SD = .90$) than small group ($M = 1.67, SD = .90$), $F(1, 419) = 4.79, p < .05, \eta^2 = .01$. Although group size had a marginally significant effect on respondents' desire for control during the preparatory phase of facility set up (e.g. in deciding which people with ID would be allowed to move in), $F(1, 419) = 3.20, p < .10, \eta^2 = .01$, the pattern of means was unexpected. In particular, respondents indicated a greater desire for influence in response to a small ($M = 3.45, SD = 1.19$) than a large group ($M = 3.25, SD = 1.21$). Perhaps, this may be due to a tendency to see, for example, selection of residents as a less meaningful response option in the case of a larger group.

Neighbouring behaviours

Respondents had a stronger preference for solving a neighbouring problem with staff while expecting neighbours with severe ID ($M = 4.11, SD = .99$) than expecting neighbours with mild ID ($M = 3.90, SD = 1.02$), $F(1, 419) = 5.18, p < .05, \eta^2 = .01$. Furthermore, respondents had a weaker preference for solving a problem related to neighbouring with residents themselves when responding to a large ($M = 3.53, SD = 1.22$) than a small group ($M = 3.76, SD = 1.33$), $F(1,$

419) = 3.36, $p < .10$, $\eta^2 = .01$. No effects of group size and level of ID on respondents' positive or negative evaluation of being a volunteer were found.

Planned comparisons

In Table 3.1 we report the results of two planned comparisons that were performed to more specifically demonstrate the way in which particular combinations of group size and severity may intensify or weaken social rejection. (Although we could have formulated a single contrast for the four means, the two proposed orthogonal contrasts provide a more specific and stringent tests of our hypotheses.) In particular, the first contrast tested in Table 3.1 expresses that a large group of people with severe ID arouses more negative (and less positive) responses than a small group of people with mild ID. This would only be an informative result for those variables for which we did not yet show that severity and group size have main and additive effects. To test the hypothesis that group size and severity cause similar, moderately negative, responses when only one of these factors is held at the more threat arousing level (either a large group of people with mild ID, or a small group of people with severe ID), we calculated a second contrast, yet, this time requiring that the test should result in a non-significant outcome, with small t -values and large p -values.

Table 3.1 shows that for 9 out of 14 dependent measures, both hypotheses could be simultaneously confirmed. The failure to confirm the hypothesis for the different traits is unsurprising when it is assumed that their attribution should only be affected by severity of disability. Interestingly, however, perceived dangerousness formed an exception, and this may well be due to an additional influence of group size on this variable. Also note that we were able to confirm the two hypotheses for anxiety as well.

Table 3.1 Responding to the arrival of neighbours with intellectual disability as a function of severity of disability and group size

		mild ID		severe ID		Contrast tests	
		Small group	Large group	Small group	Large group	(t values)	
Dependent measures						-1 0 0 1	0 -1 1 0
Acceptance	M	3.36	2.96	2.94	2.74	-3.70***	-.16
	SD	1.13	1.23	1.18	1.25		
Traits							
Sociability	M	4.02	3.96	3.92	3.95	-.74	-.50
	SD	.55	.56	.62	.63		
Vulnerability	M	3.92	3.83	4.20	4.24	3.08***	3.57***
	SD	.81	.75	.67	.77		
Unpredictability	M	3.31	3.34	3.61	3.66	3.25***	2.59**
	SD	.73	.79	.77	.86		
Dangerousness	M	1.88	2.02	2.00	2.16	2.13*	-.45
	SD	1.02	.92	.92	.90		
Emotions							
Sympathy	M	3.07	2.99	3.06	2.82	-2.02*	.66
	SD	.78	.80	.77	.91		
Anger	M	1.66	1.88	1.92	2.06	3.17***	.36
	SD	.81	.90	.90	.98		
Anxiety	M	2.33	2.42	2.59	2.58	2.08*	1.29
	SD	.82	.89	.88	.89		
Preferred preparation							
No preparation	M	1.78	1.43	1.57	1.55	-1.86*	1.19
	SD	.96	.79	.82	.94		
Open house	M	3.99	4.18	4.03	4.15	1.15	-1.09
	SD	1.11	.92	.98	1.06		
Influence on decisions	M	3.47	3.29	3.43	3.20	-1.63	.84
	SD	1.19	1.16	1.19	1.27		
Neighbouring behaviours							
Solving problems with staff	M	3.88	3.93	4.11	4.11	1.72*	1.34
	SD	.97	1.06	.99	1.00		
Solving problems with residents	M	3.85	3.52	3.68	3.53	-1.78*	.91
	SD	1.11	1.25	1.32	1.41		
Willingness to be volunteer	M	3.09	2.89	2.80	2.82	-1.67*	-.56
	SD	1.20	1.34	1.10	1.20		

ID = intellectual disability. Significance (one-sided test) is indicated as follows: * $p < .05$. ** $p < .01$. *** $p < .001$.

Discussion

Results of the present study confirm that group size and severity of a stigmatising condition have additive effects on cognitive, emotional, and behavioural reactions in the context of neighbouring involving people with ID.

In addition, the hypothesis that the particular combinations of group size and severity may strengthen or weaken the threatening nature of one of the two features was also largely confirmed. Taken together, these results may have both theoretical and practical importance.

Although the effects of severity on stigmatising responses as well as sympathy are well documented (e.g. Bos et al., 1999; Crandall & Moriarty, 1995; Dijker & Koomen, 2003), the present study demonstrated these effects specifically in the context of neighbouring and intergroup contact with people with ID. The results suggest that during anticipation of contact with people with ID, severity primarily is associated with negative emotions such as anger and anxiety, and does not influence sympathy, despite the finding that a group with a more severe handicap is seen as relatively more vulnerable. Two possible explanations for this may be given. First, compassion with people with severe ID may be more easily aroused during face-to-face contact than during anticipated contact. Complimentary, fear seems an emotion that seems especially relevant when *anticipating* contact with a dangerous situation (which, of course, is precisely the meaning of threat). Second, it may be that despite higher perceived vulnerability of people with severe ID, respondents anticipated considerable burden and annoyance, with the resulting irritation inhibiting feelings of sympathy.

To our knowledge, this is the first time that the social consequences of group size have been demonstrated by experimentally manipulating this variable in terms of a clearly perceptible increase in the number of group members to be encountered. (Parenthetically, we have not been able to demonstrate that the effects of group size were exclusively due to anticipating contact with an outgroup. In particular, merely anticipating the arrival of 12 new neighbours may also evoke threat.) The obtained effects of group size generally agree with what has been found in other studies on intergroup relations (e.g. Schlueter & Scheepers, 2010). Yet, our findings add to the understanding of the threatening nature of group size by showing that this factor may combine with another threatening feature of outgroups (severity of deviant condition) in such a way that experienced threat may be either amplified, weakened, or kept at a moderate level.

Our experimental manipulation of severity and group size represents an addition to the more common research on deinstitutionalisation and social integration of groups with special needs (e.g. Arens, 1993; Cowan, 1999; Hudson-Allez & Barrett, 1996; Robertson et al., 2005). This research area is characterised by broad conceptions of neighbourhood responses to social integration or fails to make use of an experimental approach and specific

measures of psychological processes. Our study suggests that experimental manipulations of severity and group size not only influence perceptions and emotions, but also specific behaviours that may influence the success of attempts at social integration. For example, when planning to move large groups with severe ID into neighbourhoods, policy makers not only should anticipate more opposition, but also stronger needs for preparation among next door neighbours. The latter may be dealt with by particular educational efforts (an approach which was found to be effective for favourable neighbourhood responses in the long term, e.g. Cook, 1998; Zippay, 1997). As another example, and in line with our previous findings in a qualitative setting (Van Alphen et al., 2010), it also seems useful for policy makers to anticipate that neighbours have a tendency to approach staff (especially when expecting more threatening confrontations) rather than residents, which may eventually prevent interpersonal relations with the new neighbours to develop.

Despite the relative advantages of the present study it should be kept in mind that we did not study real but anticipated contact between neighbours. Although more difficult to study experimentally, future research should examine what happens when new neighbours actually meet and how the observed behaviours are influenced by initial reactions as measured in the present study. Nevertheless, other research suggests that a better understanding of the effects of merely imagining intergroup contact may be valuable in its own right. For example, Crisp's work (e.g. Crisp & Turner, 2009) shows that merely imagining intergroup contact of a relaxed and comfortable nature has a positive influence on intergroup attitudes. The present study, however, suggests that the negative consequences of anticipating anxiety and irritation should also not be underestimated. Furthermore, one should also ask to what extent actual contact with an outgroup, especially when its members considerably differ in appearance and behaviour from the ingroup, frustrates positively toned images.

Going back to the situation described at the beginning of our paper, it may thus be quite likely that neighbours would anticipate a group with some threatening characteristics planning to move into their neighbourhood with some trepidation. When the condition of this group is of a more severe nature, or when this group would be rather large, it seems likely that elevated anxious or angry feelings may need to be addressed first, before this group would be welcomed in a neighbourhood.

Part II

ACTUAL INTERPERSONAL CONTACT
BETWEEN NEIGHBOURS WITH AND
WITHOUT INTELLECTUAL DISABILITY

Chapter 4

The Significance of Neighbours: Views and Experiences of People with Intellectual Disability on Neighbouring

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Abstract

People with ID who live in regular neighbourhoods have experiences with their neighbours which are important to understand when studying social integration. This study describes and analyses the opinions on, and experiences with, neighbour relationships of 39 people with intellectual disabilities living in neighbourhood housing facilities. We found that, while the views of people with ID on 'good neighbouring' were consistent with 'neighbouring' described in sociological literature, their experiences may be influenced by an organisational context, the tendency to formalise relationships, and apprehension towards meeting unfamiliar people. Understanding influential factors to neighbouring for people with ID may shed light on the processes involved in social integration of people with ID at a neighbourhood level. This paper contributes to understanding the opinions of people with ID on satisfactory neighbourhood relationships, and explores opportunities to improve them.

Introduction

As people with intellectual disability (ID) move from traditional segregated care facilities into care in regular neighbourhoods, they form their own experiences with neighbours. These neighbourhood relationships are interesting for researchers studying social integration of people with ID in neighbourhoods, which seems limited (e.g. Cummins & Lau, 2003; Myers et al., 1998).

Sociologists studying social cohesion in contemporary neighbourhood are also interested in neighbour relations and their ideas may apply to neighbourhood integration of people with ID as well. In addition to their ideas, there are many views from professionals and policy makers on what may constitute neighbourhood social integration of people with ID. However, little is known about what people with ID experience or find important in this respect. This study is an attempt to gain insight into the lived experience of neighbouring by people with ID by inviting them to describe and evaluate the interactions or relationships they currently have with their neighbours. They were also asked for their ideas about good neighbourly relationships and about the factors that might influence these relationships.

In the following section, some theoretical background on neighbour interactions and the value of neighbours from sociological literature is given as well as its implication for understanding social integration of people with ID in neighbourhoods.

Neighbouring and the value of neighbours

Urbanisation, use of new technologies such as the Internet and increased mobility of individuals have caused sociologists, such as Putnam (1995), to argue the demise of community and social capital in contemporary society. It is possible to extrapolate this to contemporary neighbourhoods, which might have been tight-knit communities in the past, but now may have neighbours live as ships passing in the night. Consequently, one may argue that by the lack of community in a neighbourhood, neighbours may be considered irrelevant to one's quality of life. However, research shows that neighbours and neighbourhoods do have an effect on health (Walker & Hiller, 2007; Weden, Carpiano & Robert, 2008), emotional wellbeing and feelings of safety (Farrell, Aubry & Coulombe, 2004; Sampson, Morenoff & Gannon-Rowley, 2002).

Indeed, while one's social network is likely extended significantly beyond one's neighbourhood, it does encompass it. Forrest and Kearns (2001) argue that sociologists have a tendency to overlook the significance of the small-scale

domesticity of everyday life, which suggests a sense of cohesion in a neighbourhood. Research (e.g. Unger & Wandersman, 1985; Völker, Flap & Lindenberg, 2007) has shown that neighbours do have ties and engage in interactions that have meaning and signify neighbours' specialised role in each others' social network.

These mundane everyday interactions with neighbours are what Unger and Wandersman (1985) refer to as the social interaction component of neighbouring. Briefly, neighbours may engage in social, instrumental and informational support. Social support refers to superficial exchanges on the basis of sociability: greetings, small talk, providing small favours when the opportunity arises. Instrumental support is more committed than incidentally exchanging favours and relies on reciprocity. Neighbours engage in informational support when they use their informal contacts to exchange information about developments in their neighbourhood, where to find a good household help or how to properly raise one's children.

Several factors may influence the extent to which neighbours engage in neighbouring (Forrest & Kearns, 2001; Skjaeveland & Garling, 1997; Unger & Wandersman, 1982). For example, the physical lay-out of a neighbourhood can provide opportunities to stimulate interaction by common or open spaces such as porches, driveways and bordering gardens. Also, some neighbours (e.g. families with children or people with limited mobility) engage in more neighbouring because they have a higher need for it.

Thus, neighbouring can provide people with the means for bridging weak network ties that have potential for social capital (it goes beyond the scope of this paper to fully discuss the particulars about the theory of social capital and the value of weak ties. For an overview, see Carpiano, 2005; Granovetter, 1983). Neighbouring also has a flipside: engaging in excessive neighbouring (e.g. gossiping, placing excessive demands on neighbours or disagreeing on issues of social control) can result in environment spoiling (Ebbesen, Kjos & Konecni, 1976) and have an effect on stress levels and safety feelings (Paquin & Gambrill, 1994).

Neighbours with intellectual disability

In the afore-mentioned neighbouring literature the possibility that one party might have a disability is largely ignored. Similarly, in the field of ID, when discussing neighbourhood integration of people with ID, neighbours seem largely ignored or have an ambiguous role. Here, research attention is more directed towards evaluating (and combating) the existence of neighbourhood negative attitudes when a home for people with ID is introduced in a

neighbourhood (e.g. Hudson-Allez & Barrett, 1996; Overkamp, 2000; Robertson et al., 2005; Zippay, 1997). This is no insignificant effort, as cases of neighbourhood hostility are certainly known (e.g. Collins & McConkey, 2007; Whittell & Ramcharan, 2000). However, when open hostility is absent, it seems unclear what kind of neighbourhood relationships would be acceptable to the parties involved. For example, most people with ID participating in the study of Cardol, Speet and Rijken (2007) on community integration did not mention their neighbours when talking about feeling at home in their community.

With respect to barriers and facilitating factors to integration in community settings, there is a tension between the intentions and the reality of community care. In particular, the policy may be inadequately executed in a way that people with ID might live in a neighbourhood, while the old organisation is still providing all the services their clients may need, resulting in them not using local facilities (e.g. McNally, 2004; Overkamp, 2002). Additionally, staff play a key role in organising participation in local social meeting places, more or less smoothing interactions with other people in society, yet also limiting spontaneous interactions (Evans, Felce, de Pavia & Todd, 1992; Todd, 2000).

People with ID themselves may experience problems in the organisation of community care as well; they mention that going someplace is not easy, as money, transportation or support from staff is often insufficient (Abbott & McConkey, 2006). The physical environment, whether a home is located in an urban or rural area, may pose additional problems (e.g. busy traffic or no or incidental public transportation). Personal factors such as lacking confidence or certain skills can form a barrier to participate in social activities. Moreover, negative attitudes towards a person's disability can stop people from participating (Chenoweth & Stehlik, 2004). These factors may also influence particular experiences with neighbouring.

In this study, we examined what kind of neighbour interactions are experienced by people with ID, what neighbour relationships they prefer and what aspects they see as influencing these relationships. Using semi-structured interviews and content analysis techniques (Rubin & Rubin, 2005), people with ID were asked after their own opinions regarding their neighbour relationships.

Inclusive studies concerning different domains within social inclusion, i.e. involvement of people with ID in mainstream social domains such as residency, sports, culture and religion, have yielded valuable results (Abbott & McConkey, 2006; Barr et al., 2003; Cardol et al., 2007; Chadsey-Rusch et al., 1997; Heslop, 2005; Knox & Hickson, 2001; McVilly, Stancliffe, Parmeter & Burton-Smith, 2006). However, interviewing of people with ID is not without

its own difficulties. For example, problems of social desirability, acquiescence, comprehension and the tendency of the interviewer to shape answers have been well documented (Antaki & Rapley, 1996; Antaki, Young & Finlay, 2002; Rodgers, 1999) and should be taken into account.

Method

Informants

Data from 39 people with ID out of an initial sample of 53 potential informants were included in this study. The drop-out of 14 informants is due to consent issues (9) and validity problems (5), which will be discussed later. Twenty-two informants were female and ages ranged from 15 to 75 years old ($M = 43.6$, $SD = 14.1$). All informants were clients of a care organisation in the Netherlands that offers residential care in an institutional setting as well as care in houses in regular neighbourhoods. The organisation provides care for about 800 people with ID, 40% of them having a mild to moderate level of ID, 35% of them having a severe level of ID and another 25% of their clients have challenging behaviour issues. Although the individual level of ID of the informants is unknown to the researchers, the informants as a group were diagnosed with mild to moderate level of ID by the care organisation. All informants live in working to middle-class suburbs and small town centres; specific information such as neighbourhood social economic status is unknown. For additional information concerning the living situation of all the informants, refer to Table 4.1.

Informed consent

Informants were invited to participate by members of staff on the basis of living in a neighbourhood and being able to reasonably talk about their neighbours ('reasonably' meaning able to communicate to mutual understanding, and give opinions concerning their neighbourhood). Before the start of the study, approval of the ethics committee was obtained. First, consent from the informants was obtained using accessible information, and then from their legal representatives where required (six representatives refused consent or did not respond). Consent was also sought during the interview and three times this led to premature termination because informants either lost interest or felt the interview to be too intrusive.

Table 4.1 Description of informants' characteristics

Informant	Age	Type of home	Staff support	Total # of residents	Length of residency
Daniel	15	Detached ^a	Full-time	3	2-5 years
Hugo	15	Detached ^a	Full-time	3	2-5 years
Koen	40	Apartment	Periodically	1	>5 years
Stefan	46	Apartment	Periodically	1	'long'
Katja	48	Semi-detached ^b	Full-time	5	Unknown
Desiré	30	Semi-detached ^b	Periodically	4	<1 year
Fleur	53	Semi-detached ^b	Periodically	4	<1 year
Gerard	45	Semi-detached ^b	Periodically	4	<1 year
Greet	45	Semi-detached ^b	Periodically	4	<1 year
Karlijn	50	Semi-detached ^b	Periodically	4	<1 year
Fiona	~ 50	Semi-detached ^b	Full-time	5	>5 years
Hans	51	Semi-detached ^b	Full-time	5	>5 years
Joris	40	Semi-detached ^b	Full-time	5	>5 years
Vera	40	Semi-detached ^b	Full-time	5	'long'
Jasper	17	Apartment ^c	Periodically	1	<1 year
Barbara	34	Semi-detached ^b	Full-time	5	'long'
Yolande	39	Terraced ^d	On call	3	1-2 years
Angelique	21	Terraced ^d	On call	3	> 5 years
Nienke	20	Terraced ^d	On call	3	'long'
Sander	25	Semi-detached ^b	Full-time	5	>5 years
Bauke	36	Semi-detached ^b	Full-time	6	1-2 years
Sam	47	Semi-detached ^b	Full-time	6	1-2 years
Gerrit	45	Semi-detached ^b	Full-time	6	2-5 years
Hanneke	40	Apartment ^c	On call	1	1-2 years
Claire	55	Detached	Full-time	9	2-5 years
Lia	63	Detached	Full-time	9	2-5 years
Marjo	46	Detached	Full-time	9	2-5 years
Pieter	51	Apartment ^c	On call	1	2-5 years
Sandra	43	Semi-detached ^b	Full-time	6	>5 years
Carlo	49	Apartment ^c	On call	1	2-5 years
Jan	41	Semi-detached	Full-time	10	<1 year
Eefje	47	Apartment ^c	Full-time	5	2-5 years
Maria	56	Apartment ^c	Full-time	5	Unknown
Hetty	75	Apartment ^c	Full-time	6	'short'
Thea	63	Apartment ^c	Full-time	6	'short'
Nico	51	Apartment ^c	Full-time	6	1-2 years
Nelly	67	Apartment ^c	Full-time	6	>5 years
Dave	~ 40	Apartment ^c	Full-time	6	'long'

^a Living with a foster parent; ^b The semi as a whole is owned by the care organisation, with six housemates with ID on either side. Sometimes it is used as a single house by having a connecting door; ^c Congregated setting: These apartments are part of an apartment building for people with ID supported by the care organisation; ^d Congregated setting: These are part of a row of about ten terraced houses for people with ID supported by the care organisation.

The interview and materials

Informants were asked about their neighbouring experiences in a semi-structured interview setting, with a topic list of starter questions to guide the interview. Instead of using a standardised questionnaire with a fixed order of questions, a topic list can be used in a flexible manner to adapt the interview to differences in communication skills of the informants. Also, it allows informants to exercise control over the direction of the interview and depth of the discussion.

We first asked about informants' daily life, work, hobbies and friendships, in order to get acquainted with the informants' life. As was found in previous research, several aspects of the lives of people with ID may create barriers to social inclusion (Abbott & McConkey, 2006), which could have an effect on neighbouring experiences as well. Further, the topic list covered themes directly related to neighbouring experiences (Forrest & Kearns, 2001; Skjaeveland & Garling, 1997; Skjaeveland, Gärling & Maeland, 1996; Unger & Wandersman, 1982, 1985), e.g. 'Do you know, see, speak to, visit, help out some of your neighbours?' Additionally, informants' wishes concerning neighbouring and possible barriers to neighbouring they experience were asked about, e.g. 'If you want to get to know neighbours, is this easy or difficult, and why?' The topic list can be obtained from the first author. The conversation sometimes crossed over to social interactions with 'strangers' (i.e. non-neighbours) in general. To provide a physical context for the discussion, pictures of the informants' house, their neighbours' houses and street were presented.

The interviews took place at the informants' house and lasted up to an hour. At the start of the interview, introductions were made (the interviewer was LvA) and study particulars were discussed: the topic of the interview, anonymity and how the data would be processed and published, and the right to revoke consent at anytime without question. A member of staff was present during some interviews, to help with mutual understanding if necessary, or if the informant so wished.

Analysis

The interviews were first assessed on quality. In the case of five interviews, problems with validity (a combination of comprehension problems, social desirability issues or the interviewer or support staff shaping answers) were thought to be too great to include them in the study. The remaining 39 recorded interviews were typed out verbatim, using pseudonyms to guarantee

anonymity. These texts were imported in NVivo, and analysed using content analysis techniques proposed by Rubin & Rubin (2005). Phrases and short parts of texts were coded to get an overview of the topics discussed. The topic list on which the questions were based provided the biggest share of codes. Codes such as 'knowing neighbours', 'seeing' or 'talking to neighbours', 'helping' and 'visits' were used to describe typical encounters with neighbours.

The contexts in which neighbour encounters took place were separately coded in order to understand influential factors to neighbouring. For example, codes such as 'work and leisure' and 'staff support' gave insight into where and how informants would have encounters with neighbours. If related, these codes were grouped in larger themes, in this case 'the organisation'. Other phrases or parts of text related to these themes sometimes gave deeper understanding to an issue. For example, the use of 'jargon' by informants was informative in understanding the theme of 'the organisation', and thus was separately coded. For an overview of the coding structure relevant to neighbouring, refer to Table 4.2.

Table 4.2 Overview of themes and codes relevant to neighbouring

	Theme	Codes
Neighbouring	Superficial neighbouring	Knowing neighbours See neighbours around Greet/ talk to neighbours
	Involved neighbouring	Helping and reciprocity (Coffee) Visits
	Feeling at home	Feeling at home Bad neighbours
Influencing factors	The organisation	Work and leisure Jargon Staff support and control
	Formalisation of relationships	Volunteers
	Apprehension towards interaction	Taking initiative Insecurities related to disability
		Experience of teasing, violence or exclusion

Results

In this section, informants' experiences with neighbouring, as well as the relative importance of neighbours in their life and factors that influence satisfactory neighbourly contact, are presented. This is done using the coding

structure of Table 4.2; with the headings referring to the general themes and covering the separate codes within the respective themes.

Neighbouring

Superficial neighbouring

The most common kinds of contact informants had with their neighbours could be characterised as being of a superficial nature. Half the informants knew a few neighbours, mostly next door. Some informants living in a congregated setting would name their housemates or neighbours with ID next door, which seems logical, but some others would mention the people with ID living a few blocks away in another house owned by the organisation and five mentioned neighbours who were their or their housemates' volunteers (this will be discussed later). Also, two informants had little understanding that people were living in other houses on their street, and didn't know them. 'Knowing neighbours' seemingly meant knowing a name and having some kind of established relationship by undertaking activities. 'Knowing neighbours' by mere facial recognition may be insufficient. Perhaps by that definition, no informant felt the need to know all their neighbours.

Twenty-five informants reported seeing their neighbours in the street and exchanging greetings. It was very important not to be ignored and get a greeting back. To them, strangers can be good neighbours, yet still relatively unknown, as long as they are polite and proffer greetings when they see them in the street. And this goes both ways:

Pieter: 'And then you'll be thinking "why does that guy not say anything"? (...) Yeah, or I'll say good day. You should. Doesn't matter where you are, or in the rain. Always be proper. Otherwise, I don't need to live here.'

Those who did not greet mostly seemed not to 'know their neighbour' and perhaps considered their neighbours virtually non-existent, or not recognisable enough to warrant a greeting.

Most informants expressed no wish to know more people from their neighbourhood or to intensify the relationships they currently had with their neighbours. The reasons given were manifold; it was important to know some people from their neighbourhood, yet knowing everybody was overdoing it, because it might cause an extra burden while the informant preferred things to be quiet. Also, strangers were felt to be a little scary sometimes, or perceived as

butting in. Nonetheless, these small exchanges, sometimes merely seeing neighbours, or greeting them and exchanging small talk, were all considered important.

Fiona: 'Yeah, yeah! "Welcome, good morning Fiona, how are you?" "Fine!" That says it all, doesn't it?'

Small talk was exchanged on some occasions, but rare. One informant would meet his neighbours at the pub, and another three mentioned the local supermarket. Some mentioned open days and neighbourhood barbecues in the past, which provided an opportunity to meet and talk with neighbours. These interactions with neighbours were enjoyable and many would welcome invitations from neighbours for a visit or a party. For seven informants, though, whether the interaction with another person or the prospect of a party was most enjoyable was unclear.

Involved neighbouring

Ten informants asserted to have received some kind of help from their neighbours. Neighbours would watch the house while on holiday, give a hand moving in, donate items such as toys or clothes, help in an emergency or simply return a ball kicked over the fence. Although this help was much appreciated, with these neighbours being 'very nice people' and making them feel welcome, returning a favour was a more unfamiliar concept for most of them. Only four recognised the necessity.

Koen: 'When she's in the shop with me, or comes to me in the shop for her shopping. Then I'll ask her, "should I bring something down for you?''

One informant, Koen, also mentioned helping out many times at village parties. Within her own community, one informant mentioned a vivid exchange in goods and staff support between her house and another house owned by the organisation two street blocks away.

Coffee visits were a regular occurrence for 16 informants. For six informants a neighbour would regularly visit them and their housemates. In other cases, the visiting neighbour was a volunteer, a member of staff or person with ID. These visits were most likely in their house and informants stressed the importance of hospitality.

Jan, thinking about the apartment he wants: 'Little table should be there, that you can receive people. And a coffee machine, you should have.'

Interviewer: 'Do you do anything for [volunteer]?'

Marjo: 'Yes, pour coffee.'

The significance of neighbours for feeling at home

An important observation to make is the limited role neighbours seemed to play when informants were asked about 'feeling at home'. To feel at home, the house needed to be 'nice', the atmosphere in the neighbourhood needed to be just right, informants needed to feel safe, calm and at ease. A good relationship with housemates was also important: informants needed to be able to talk to them and relate to them. However, when neighbourhood relations were tense, when there were instances of public aggressiveness (teasing and name-calling), neighbours were annoying (e.g. loud music, not keeping a clean house) or ignored them, this sense of feeling at home was challenged.

Karlijn spoke of some neighbours setting up a petition protesting their arrival in the neighbourhood and another group of neighbours setting up a competing petition to welcome them.

Interviewer: 'What did you think of that?'

Karlijn: 'Well . . . Every person with a disability, you have to give them a chance, I think. (...) They should not be put in a corner. Every person is unique, and that is often, very often forgotten.'

Interviewer: 'When those neighbours started a petition, that was not very nice, but when there was a counter petition...'

Karlijn: 'Things were nice again.'

As such, neighbours may be deemed irrelevant, providing that they are openly kind or convivial and slightly in the background.

Facilitating factors and barriers to neighbour interactions

The organisation of care frames context and opportunities

The residence of some informants could act as a physical barrier to neighbour interactions, seemingly indicative of the organisation's influence on

opportunities for neighbouring. The home of eight informants, congregational in nature, made superficial interactions with neighbours virtually impossible: there were no common spaces (such as bordering gardens, a shared driveway) to meet or even see other people. Moreover, when going out to work, visiting a pub or going for a walk, they would go as a group. Also, a mini-van often collected residents and dropped them off from work or their daily activity centre. Those who travelled by bicycle or public transport had more opportunities for casual interactions with neighbours, and tended to know more of them. The few informants having a job in their neighbourhood (e.g. working in a local supermarket) met neighbours in that setting.

Most social activities for informants took place at the care organisation's various social clubs. This was a stark contrast to the example of the two boys living with a foster parent, with whom they would go on visits with and play in the local football and netball team. However, one informant made clear that this 'organisational domain for social activities' was not necessarily a bad experience.

Gerard: 'I think it's a shame [that the organisation closes social clubs at their old institution grounds]. And now they want to quit the drum band, I said, listen here, I don't agree! I can tell on behalf of a lot of clients (...) that those things should stay. Yeah, have to go and look here in the village, they say, you come with me and we'll go see (...) but for us it is very hard to, people with an intellectual disability, to keep up.'

The scope of the influence of the care organisation could also be seen in the use of jargon by quite a few informants. For example, informants occasionally labelled themselves ('clients'), where they lived ('community home') and their relationships with others ('my volunteer', 'the other residents', 'the interns') using words that seemed to indicate embedding in an organisational structure.

Gerard: 'I talk for clients.'

Nelly: 'That's an outsider, she comes to work voluntarily. She doesn't get paid, but just comes.'

Staff, themselves, would sometimes impose rules limiting mobility and possibilities for interactions. One informant mentioned not being allowed to

talk to strangers and another six informants mentioned not being allowed to go out walking.

Jan: 'I'm not allowed to do anything yet. I've been here so many years, I'm not allowed to do anything. Back then at —, I was allowed to ride my push bike to the farm on my own, but Ruud says here I can't. So I take the bus. [The traffic is] too busy.'

However, staff could also serve as facilitators in creating opportunities to meet neighbours. Eight informants mentioned past or future open days, neighbourhood barbecues or parties organised by staff.

Interviewer: 'So when you had that party, and people came to get to know you, do you think you weren't strangers anymore?'

Carlo: 'Yeah look, them, we do think so. (...) Yeah. But still, I quite like it, 'cause first [we] said nothing to each other here.'

Some informants mentioned staff taking them to local activities and having introduced them to new neighbours. Staff could also intervene and smooth over problems with neighbours, as one informant explained when neighbourhood children were troublesome and another told about a case of physical abuse by a neighbour with a mental illness.

Staff members were also influential in life choices to varying degrees for virtually all informants. For example, staff determined the number of chores to do in the house, when and where to smoke, when one informant would be helped in and out of bed and allowed to watch television. For three informants, these represented significant choices as big as whether to move house or where to move to, and to what degree one would be achieving independency. For 11 informants, being able to make independent choices without the 'interference' of staff was a great good and they were proud of it.

Jasper: 'I would just like to supervise myself.'

While not directly related to neighbouring, it does indicate a level of control that places neighbouring in a certain context.

Formalising relationships

Neighbour relationships that went beyond the superficial tended to be formalised in the sense that they mainly concerned volunteers or staff living

close by. Many informants had a volunteer who was not necessarily a neighbour. Volunteers were very important to the informants, making arrangements for them to go places and engage in activities. These volunteer relationships were typically organised around a set time and activity. During two interviews, informants were anxious to finish because their volunteer would arrive shortly and they seemed afraid to miss being able to go to town. One informant gave a powerful explanation of the kind of relationship with her volunteer (a neighbour from her previous home).

Nelly: 'No, you know what I always say to Annie says, Ma'am says "you cannot say that". Annie says "I am not", but then I take her like a mother, see. Then I say 'mum', but Annie says to me "you shouldn't say that, you should always say, I am your friend". But not mother. You have to say friend. Volunteer, that is er..., that is not a mum, is it? But I do call her mum. I always call her mum, but it is not a mum.'

Apprehension towards interaction with others

There seemed a preference for social contacts to be with other people with ID, family or volunteers, rather than people from outside the context of the organisation. Nearly all informants recalling their relocation remembered being a little ill at ease with their neighbours at first. They had to get used to their new surroundings, and to the new, unfamiliar people next door. When asked whether people would like to meet their neighbours, many would immediately respond that if they received an invitation, they would. There seemed to be an overall lack of initiative.

Nelly: 'But I have to say, when you won't say "Nelly, come and visit us once", then I won't go. When the people don't invite me, miss, then I won't go. I am not going to beg, "miss, can I visit?" (...) And when the people don't come, miss, then I won't have visitors. No, I can't help it, miss, then I'll be in that chair there all day.'

As mentioned earlier, specifics of a disability may be an important factor. Some saw certain sensory aspects of their disability being a problem in their interactions with others. Some expressed a fear that the other might not understand them, or they were not able to understand the other, felt 'different',

and that neighbours should know 'about them'. A certain frustration or insecurity with meeting unfamiliar people was expressed by a few.

Fleur: 'Yeah, I'd like to know them, but I don't know if they would like to. I'd like to try, but if I can't do it, I cannot do it. Then Fleur can't do it. No, you have to stay calm then, stay calm.'

Perhaps, this insecurity was fed by negative experiences in relationships in the past. Four informants reported negative reactions to them (in their neighbourhood or in town), name-calling and physical abuse.

Carlo: 'Yes, it feels, then I feel right scared, so yeah.'

Interviewer: 'Cause perhaps other people might not be nice?'

Carlo: 'Sometimes, just... or scared or something. But if not, could go wrong too, then.'

Interviewer: 'And what would happen if things go wrong? What happens then?'

Carlo: 'When they like, hit you like, their hands, then there'll be cursing, though.'

Discussion

Experiences of neighbouring

Experiences of neighbouring for people with ID seem not too different from 'neighbouring' for non-ID people as mentioned in the introduction (Unger & Wandersman, 1982, 1985). Most know some neighbours and greet them, and some exchanged favours. A distinct group, on the other hand, seems relatively unaware of their neighbours, in knowing and greeting them, which could be attributed to several influencing factors.

Neighbourhood contact for people with ID does not seem to relate to a sense of belonging or feeling 'at home'. The appearance and safety of the house and neighbourhood, agreeable housemates and a freedom to do as one pleases were much more important. Similar findings were reported by Cardol et al. (2007) in their study. However, in agreement with the general need to limit neighbouring to superficial yet friendly interactions (Ebbesen et al., 1976; Forrest & Kearns, 2001; Paquin & Gambrill, 1994), the informants in this study did not seek a relationship with all neighbours, and extensive contact or interference was found to be annoying or damaging a sense of feeling at home

(e.g. loud music, teasing). Moreover, neighbouring that moved beyond the superficial more likely involved volunteers and nearby living staff.

Facilitating factors and barriers to neighbouring

The organisation defines context and opportunities

As mentioned previously, the physical lay-out of a neighbourhood may determine opportunities for neighbouring (Skjaeveland & Garling, 1997). In addition to the physical lay-out of their neighbourhoods, the informants in this study also experience a typical context within which neighbouring opportunities could be both discouraged and encouraged. For example, the limited neighbouring or even neighbour awareness of some informants could be related to how their lives are organised. It was striking to notice the potential of staff (or the care organisation as a whole) in setting the parameters of (social) life within which informants could exercise control. For instance, the lay-out of the home of some informants limited their ability to see or spontaneously meet their neighbours. Furthermore, choices concerning daily and social activities, and the social relationships of some originated and were defined in the context of the organisation. Even doing favours, like in the example of a goods exchange between two nearby community homes, sometimes seemed to happen within the organisational context. This reinforces the strong bonds with the organisation and perhaps creates a self-fulfilling prophecy towards limited neighbouring.

Many informants, though, appreciate the assistance staff or the organisation can give when it comes to problems with neighbours or in organising work and social events. As such, and somewhat ironically, staff, or the organisation of community care, may both limit and facilitate interaction with neighbours. This is an issue noticed in previous research, for example, by Todd (2000) who quotes Schmidt in saying that the staff member seems like a tour operator insulating travellers (i.e. people with ID) in a 'tourist bubble' (i.e. 'the organisation context') while being out in the 'host culture' (i.e. society). The balance between interfering and assisting seems delicate, perhaps even more so when the level of ID or the physical environment creates more safety or accessibility concerns. This observation should concern staff and policy makers (for a discussion on organisational care helping and hindering natural interactions, see Schwartz, 1997).

Formal relationships and neighbouring

A salient feature of neighbourhood relationships for people with ID is the tendency to formalise involved neighbouring, thus making for a rather dependent one-directional or care-related relationship. There could be many reasons for this, one being that our society seems organised in such a way that many relationships that involve care are formalised. Schwartz (1997) argues that people's trust in 'the system' allows them to step back and not take action when needed. Perhaps this could work both ways, in the sense that when one does accept responsibility, this should be recognised by getting a formal position in the system (i.e. being a volunteer).

In terms of neighbouring, formalising relationships might take away the opportunity for people with ID to engage in casual interactions with their neighbours, going against the typical superficiality of regular neighbouring (Forrest & Kearns 2001). This in turn may reinforce organisational thinking. Paradoxically, the phenomenon of volunteers, with strong ties to an organisation, may stand in the way of regular neighbouring, while at the same time provide valuable opportunities for activities. In order to profit from potential social capital in neighbourhoods, it may be fruitful to consider superficial neighbourhood contacts instead of formalising or directing them.

The informants of this study did not appear to mind whether their neighbour is a volunteer or not, appreciating the contact whatever label is given to it. Other studies have shown how important reliable and trustworthy people are to the social integration of people with ID (Jackson, 1997; Jameson, 1998), and volunteers seem to be most reliable and willing to overcome barriers such as logistical problems and lack of reciprocity in relationships. The question then is, whether neighbours and people with ID see possibilities to engage in neighbouring without it being contractual, and how reciprocity comes into this.

Apprehension towards unfamiliar people

For the informants in this study, it seemed difficult to meet unfamiliar people and they showed a lack of initiative towards engaging with neighbours. Interaction would wholly depend on the neighbours' discretion. There might be several reasons for this. For example, it may be possible to relate this attitude to learned helplessness, which Goffman (1961) described in the context of 'total institutions'. Individuals with a history of institutional care might become part of the system and stop making certain decisions. This might be reinforced by the controlling role of staff and occasionally volunteers.

There may also be a certain insecurity to approach others because past experiences have taught some people to be wary, or they do not feel competent enough, and think that their disability may frustrate interaction. Both issues are also mentioned by people with ID interviewed by Abbott & McConkey (2006). It is uncertain to what extent the informants felt to be stigmatised and whether this related to their weariness. However, by mentioning preferring the company of others with ID and experiencing occasional negative reactions to them, they may have felt that others left little room to accommodate for them in interactions. Interactions between people with and without disabilities can be fraught with awkward moments that can create certain anxieties to both interaction parties (Hebl, Tickle & Heatherton, 2000). This is an issue that needs to be further explored in terms of neighbouring encounters.

Study Limitations

As noted earlier, it is important to be aware of the particular validity problems with this type of research (Antaki & Rapley, 1996; Antaki et al., 2002; Rodgers, 1999). Special attention was given to irregularities during the interview or in the transcripts. For example, it was noticed that the presence of staff could help in providing background information, but also create a test-atmosphere stimulating informants to give 'correct' or 'complete' answers (e.g. "And who else do we visit? We go to. . . ?"). Incidences of informants being in a 'yes-state' (i.e. answering 'yes' to several questions in a row, perhaps because of a tendency to comply) may have obscured their true opinions in answering subsequent questions. In some occasions, questions had been posed incomprehensibly, which, together with the nervousness on the part of some informants to 'do well', caused moments of discomfort or unreliable answers just to 'say something'. In all these cases, actions were taken to both settle the need to 'do well' or take note by marking such a section to not take answers at face value.

As the result section shows, not all topics and experiences were addressed by all our informants. This does not necessarily imply that these experiences are (un) common or irrelevant; a high or low number of informants sharing an experience might be based on coincidence, individual differences in communication abilities or the flexible use of the topic list. For example, occasionally the topic list was kept out of view to prevent a test-atmosphere making informants nervous. As a result, not all questions were posed exactly the same. While many questions were phrased as an open-ended question, for some informants it was found that closed-ended questions were better understood. Furthermore, not all informants had the ability to comprehend

complex questions that involved conditional statements or extensive recall, or verbalise emotions and could only mention a few names or simple preferences. It was found important to include these people's opinions nonetheless.

Notwithstanding these particular threats to validity, the stories of all informants hopefully provided a piece, however small, of the puzzle of what neighbouring means for people with ID.

Directions for future research

In this paper we presented a broad picture of activities in the neighbourhoods of people with ID from their own perspective. It has yielded a general but variable picture of neighbouring experiences, probably as a result of different barriers or facilitating factors in neighbouring for informants, or as a result of the wide differences between individual characteristics of the informants themselves. While it is clear that the current study is less suitable to unravel complex relations and interactions between the many determinants of good neighbouring, the present study offers valuable directions for future research.

First, we have the impression that the level of ID or other personal characteristics (a history of institutional care, age and personality, etc.) greatly influence how people with ID interact and experience their relationships with their neighbours. Contextual aspects, such as facility characteristics (staffing, size, etc.), may coincide with personal characteristics and define the playing field of neighbouring to a certain degree. The relation of these factors to neighbouring activities is perhaps more appropriately studied using quantitative methods.

Future research could also take into account the characteristics of the neighbourhoods in which the informants live. The neighbourhoods of our informants were more or less homogeneous. Therefore, the experience of those who live in larger or ethnically diverse areas might be different. By the same token, people with ID who live in a low-populated area may not feel their experiences sufficiently represented.

Lastly, future research could take a broader context into consideration, asking, for example, to what extent the neighbouring experiences of our informants are similar or different to the experiences of their neighbours without ID.

Chapter 5

People with Intellectual Disability as Neighbours: Towards Understanding the Mundane Aspects of Social Integration

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Abstract

Although people with intellectual disabilities (ID) are increasingly expected to relocate from traditional institutional care to 'regular' neighbourhood housing facilities and socially integrate in these neighbourhoods, little is known about how they are perceived and appreciated as neighbours. This paper reports on interviews carried out with 30 neighbours without ID who were neighbours of small-scale care facilities for people with ID. Interviews addressed the neighbours' everyday experiences of neighbouring in general, and neighbouring people with ID in particular. Neighbouring, for these informants, called for a fine balance between friendliness without over-involvement. While they were generally positive about their interactions with their neighbours with ID, it emerged that the formal nature of the care facility and the interaction style of some of the neighbours with ID often contravened informants' assumptions about neighbouring. Informants expressed concern about a possible lack of appropriate distance, reciprocity and accountability among their neighbours with ID. The nature of the care facility, with paid staff, often group activities, formal means of achieving the everyday small tasks which neighbours sometimes do for each other, and a high turnover of residents, all undermined the possibility of a typical neighbourly relationship. In conclusion, we suggest that integration of people with ID into everyday neighbouring relationships raises complex challenges for care organisations that need to find a balance between supporting the needs of people with ID they care for, adequate support and mediation for other neighbours when necessary, and all the while avoid becoming overly involved in neighbouring as a formal partner.

Introduction

In modern Western societies, neighbouring often involves keeping a delicate balance between showing a benevolent interest in the needs of neighbours and keeping one's distance, respecting neighbours' privacy and individual characteristics. The mutual skills and adaptations needed for successful neighbouring, as well as the potential for conflict among neighbours, are increasingly understood (Forrest & Kearns, 2001; Paquin & Gambrill, 1994; Stokoe & Wallwork, 2003; Unger & Wandersman, 1982). However, attempts to let members of special groups, such as people with intellectual or developmental disabilities, move from relatively isolated and large institutions into society and to encourage them to establish normal relationships with neighbours (often under headings such as participation, inclusion or social integration¹) may pose challenges to successful neighbouring, which are as yet insufficiently examined. For example, neighbours may be unsure about possibilities of approaching people with intellectual disabilities (ID) as individual and accountable neighbours, especially when living in small but still clearly recognisable care facilities with the support of staff, and appear as a separate group from other neighbours living in private, single-family houses (Cook, 1998; Currie & Aubry, 1995; Overkamp, 2002).

Social integration of groups with special characteristics and needs has been predominantly conceptualised, in the research literature, in a dichotomous manner, with neighbours viewed as either accepting or opposing the presence of these groups in the neighbourhood (Currie et al., 1989; Hudson-Allez & Barrett, 1996; Jason et al., 2005; Robertson et al., 2005; Schwartz & Rabinovitz, 2001). Indeed, it is common practice among policy makers to frame initial opposition to the arrival of care facilities for people with ID in terms of neighbours' stigmatising or not-in-my-backyard (NIMBY) attitudes or to emphasise the political equality and rights of the groups concerned (Dear, 1992; Jason et al., 2005). Studies into neighbourhood social integration tend to focus on why these reactions may occur (Graham & Hogan, 1990; Pittock & Potts, 1988; Robertson et al., 2005; Schwartz & Rabinovitz, 2001) and how attitudes may change (Hudson-Allez & Barrett, 1996; Zippay, 1997).

However, despite the relevance of these studies in overcoming barriers to the siting of community facilities, this dichotomous approach ignores the complexity of social integration in terms of neighbourhood interactions and may therefore fail to recognise opportunities for improving the quality of

¹ There is disagreement on the exact meaning of these terms (e.g. Thorn et al., 2009). We choose the term integration and require, at minimum, that the term refers to having mutually agreeable social relationships with neighbours.

neighbouring when special groups such as people with ID are involved. In particular, without denying that some individuals may be disposed to show fear, aggression or prejudice towards these groups, it may be fruitful to study social integration, like any other interpersonal relationship, in terms of interactions between individuals, taking into account their behaviours and the manner in which they are mutually perceived and responded to (Cowan, 1999; Ytterhus & Tossebro, 1999). For example, Cowan (1999) interviewed people on their thoughts and feelings about people with mental illness and, amongst other things, concluded that opinions adapted themselves to the particular context in which these people were met. In sum, it may not seem fruitful to consider all negative responses to the presence of people associated with deviant conditions in a neighbourhood to be evidence of negative attitudes or prejudice (Dijker & Koomen, 2007) or to assume that lack of opposition towards a care facility for people with ID implies a readiness to interact with these people.

The goal of this study is to uncover the details of these interactions by means of qualitative interviews with neighbours of people with ID, grouping them into factors that may impede or facilitate neighbourhood social integration. Before presenting the study, general characteristics of modern neighbouring will be discussed, as well as possible differences when people with ID are involved as neighbours.

Neighbouring in modern western society

While there is disagreement about whether modern neighbourhoods should be considered communities with strong levels of social support, cooperation and reciprocity (e.g. Putnam, 1995), sociologists studying social interactions among neighbours ('neighbouring') describe the existence of a general social structure (Forrest & Kearns, 2001; Unger & Wandersman, 1982). In this social structure, neighbours act according to general behavioural codes they see as morally desirable. By doing so, they are able to establish social order and control, and may create a sense of community and belonging (Stokoe & Wallwork, 2003). While behavioural codes may vary culturally or geographically, some general neighbouring principles seem to apply to modern Western neighbourhoods.

Contact among neighbours often involves elementary acknowledgement of each others' presence (e.g. by means of a greeting nod or wave) together with expressions of kindness, concern and appeasement (e.g. Unger & Wandersman, 1985). Despite the superficial nature of neighbouring, neighbours tend to see each other as potential sources of support that could be relied on in need (Forrest & Kearns, 2001). For example, in applying a norm of reciprocity (cf.

Gouldner, 1960), neighbours may engage in the exchange of small favours, but also often take great pains in ensuring that relationships with neighbours do not develop into close relationships with strong mutual obligations.

Often being in close proximity, aggravations among neighbours, such as noise complaints, and their effects on quiet domesticity are well known (Paquin & Gambrill, 1994; Stokoe & Hepburn, 2005). These annoyances represent a unique source of irritation which can be termed environment spoiling (Ebbesen et al., 1976). Neighbours are usually expected to be accountable if they annoy their neighbours and are expected to adapt their behaviour after receiving complaints; expectations associated with experiencing a sense of social control (Chaurand & Brauer, 2008).

In sum, neighbouring often involves skilfully keeping a balance between showing a benevolent interest in one's neighbours, together with a readiness for mutual support and reciprocity, and respecting privacy.

People with intellectual disability as neighbours

It is against the background of the abovementioned general neighbouring principles, that it may be possible to predict how people will respond when coming into contact with a small scale care facility for people with ID in their neighbourhood. These facilities, typically a regular or converted house or apartment block on a residential street housing a small group of people with ID and occasionally their support staff, stem from modern care policies for people with ID concerned with deinstitutionalisation and social integration (Beltman, 2001; Gates, 2001). Evaluative studies on social integration of people with ID who have moved from traditional segregated care in relatively isolated and large institutions to community homes have illustrated that the practical side of deinstitutionalisation policies may not always follow their intentions. For example, interaction with neighbours and participation in neighbourhood activities is sometimes limited, and residents are still largely dependent on staff or the care organisation in daily routines (Abbott & McConkey, 2006; Cummins & Lau, 2003; Overkamp, 2002; Van Alphen, Dijk, Borne & Curfs, 2009).

As such, the home, or small scale care facility, may have distinguishable features setting it apart from individual, private homes, and it may be difficult for neighbours to determine to what extent the residents are members of their neighbourhood. A neighbourhood consisting of single-family houses, particularly, may be ambivalent about the neighbouring prospects of the residents of such a home (Aubry, Tefft & Currie, 1995; Pittock & Potts, 1988).

Second, people with ID may be seen as lacking certain communication skills, and display what their neighbours may perceive as abnormal, disturbing

or unfamiliar behaviour, which may also put a strain on neighbouring. However, neighbours may also associate ID with vulnerability and dependency, and hence experience caring tendencies (Dijker & Koomen, 2007). Together, these tendencies and the experience of negative emotions may cause ambivalence and interaction uncertainty.

Third, it is expected that staff have an important role in determining the manner in which neighbours of people with ID experience neighbouring. While often not living in the neighbourhood itself, staff may function as mediator in interactions between the people with ID they care for and others in society at large (Cook, 1998; Todd, 2000). Moreover, by their mere presence, they may be perceived as part of the home and perhaps expected to engage in neighbouring.

The present research

Rather than study neighbourhood social integration of people with ID by measuring the existence of certain attitudes towards their presence, we pay detailed attention to the characteristics and behaviours of neighbours and the manner in which they are mutually perceived and responded to. In the present study, we interview people on their neighbouring experiences in general, and compare these to experiences with their neighbours with ID, who all live in small scale care facilities run by a care organisation. This study is complementary to a study into the views and experiences of people with ID on neighbouring (Van Alphen et al., 2009), in order to gain insight into different sides of the interaction.

Method

Recruitment of informants

A group of 179 neighbours of people with ID from 16 neighbourhoods were invited to participate in this study. Using Hamilton's micro-neighbourhood design (as cited in Hudson-Allez & Barrett, 1996), people from the two houses on either side of a care facility, as well as the five houses opposite, and the three houses bordering the back of the property were invited. Using this design, neighbours who were likely to see or hear their neighbours with ID were included. In three of the neighbourhoods, the care facility was an apartment block, or a house located at the end of a cul-de-sac; the nearest few houses or apartment blocks were then selected.

An information letter with reply form was sent to potential informants. Responses came from 64 addresses (36%), of which 30 were willing to participate and 8 wanted more information. The remaining 26 declined participation. Approval from the Ethics Committee of the care organisation for the people with ID involved was obtained.

Description of informants

The final sample consisted of data from 22 interviews with 30 neighbours of people with ID in 12 neighbourhoods. The informants were mostly female (20), on average 56 years old, with a range of 32–87, and lived in predominantly middle-class suburban neighbourhoods. Almost all informants lived in semi-detached or detached houses and about a third shared a property border with a home for people with ID.

Informants had on average 13 people with ID living in a home on their street, with a range of 8–20. In about half the cases, this concerned a group of people sharing two semi-detached houses (effectively a single home), in other cases it involved a larger facility such as an apartment building specifically for people with ID. The level of ID of the residents of all facilities was diagnosed by the care organisation as generally moderate in 10 neighbourhoods, mild in one and severe in another. In all but two neighbourhoods, the home employed full-time staff.

Interview and topic list

The interviews, conducted by the first author, took place at the informants' homes and lasted up to 90 minutes. The interviews were semi-structured with the help of a topic list. This list consisted of four sections; the first section contained questions to get acquainted with the informants and their neighbourhood. The second addressed neighbouring experiences with others on the informants' street, to get insight into their opinions on general neighbouring in their particular neighbourhood. The third section concerned neighbouring with the informants' neighbours with ID specifically, all the while asking for examples. The last section concerned follow-up questions to get insight into thoughts or feelings during interactions with neighbours with ID, evaluation of these experiences, and wishes for change, if any. The interviews often crossed over to general attitudes towards people with ID, the policy of community care and the meaning of social integration.

Analysis

The interviews were taped and typed out verbatim, using pseudonyms to guarantee anonymity. The data were analysed on topical content, with the objective to identify existing neighbouring principles and compare them to neighbouring experiences with people with ID. An overview of the final themes and sub-themes related to neighbouring is presented in Table 5.1; this coding structure was obtained by following four steps of analysis, using N-Vivo software. First, general neighbouring principles as mentioned in the sociological literature provided general starter themes (such as 'establishing neighbourhood membership', 'reciprocity' and 'keeping one's distance'). Additional themes emerged through reading the interview transcripts. Second, the identified themes were more clearly defined in discussion among the authors. Occasionally, this led to identifying new themes or combining others into a single one. Then, labels describing a theme were used to code the interview transcripts. Finally, the labels and data were organised in a structure to best serve the study objective, which was to compare neighbouring experiences with neighbours with and without ID and look for possible differences. The final structure in which the findings are presented can be found in Table 5.1.

Findings

In this section, the themes mentioned in Table 5.1 will be used to describe informants' neighbouring experiences. For each theme, we first describe what informants had to say about neighbouring in general and then describe the distinctive features of neighbouring with people with ID that emerged.

Table 5.1 Overview of themes

Themes: General neighbouring principles	Sub-themes: Activities, conditions or contexts	Examples mentioned by informants where interactions with people with ID differed from 'normal neighbouring'
Neighbourhood membership	Introducing oneself	Formal rather than informal introductions, turnover in staff and residents without introductions
	Being a visible and familiar face	Fewer opportunities for visibility
Day to day interactions	Acknowledging each others' presence by greeting	Staff and neighbours with ID may not greet
	Making small talk	Small talk with neighbours with ID sometimes one-directional and strained
Exchanging favours	Finding spontaneous interaction opportunities	Few opportunities for spontaneous small talk
	Creating potential for favour exchange	Few opportunities to informal favour exchange, with occasionally unfamiliar staff or neighbours with ID
	Recognising the need for reciprocity	Formal nature of care may limit opportunities to do a small favour in return
	Recognising limits to favour exchange	Tendency of neighbours with ID to depend on or expect too much of neighbours
Being considerate	Recognising (potential) incivilities	Formal care (e.g. traffic) and unusual behaviour of residents who may not be accountable give a specific nature to incivilities
	Being tolerant of occasional nuisances	Tolerance for unusual or unfamiliar behaviour of neighbours with ID sometimes strained
Keeping a distance	Making reconciling efforts	Staff and care organisation as mediator
	Recognising boundaries	Tendency of neighbours with ID to expect too much commitment of neighbours
	Finding permissible conditions for involvement	Few opportunities to find a way for spontaneous, informal involvement, without too much commitment.
General expectations of neighbouring	Recognising others as responsible neighbours with whom one can expect to engage in neighbouring	The home for people with ID and staff differs too much, in physical appearance and/or behaviour of its residents, from other neighbours to expect a 'normal' neighbouring relationship

Establishing neighbourhood membership

On the basis of facial familiarity or introductions, informants were able to tell who did or did not belong to the neighbourhood and hence could or could not be expected to engage in neighbouring. While establishing membership of neighbours with ID sometimes followed a similar pattern as with other neighbours, several differences were mentioned.

Although some informants were casually introduced to their neighbours with ID similarly to other neighbours (e.g. a member of staff would invite them over for a cup of coffee), introductions for others were often formally arranged affairs. During these formal occasions (e.g. an open day or information meeting), neighbours got information about and acquainted with the home as a whole. While these informants were aware of the particulars of the home (such as staffing, organisation of care, lay-out of the house), little was known about individual residents. Some informants spoke of a high turnover of residents, with people frequently moving in and out, sometimes without introductions or goodbyes. This high turnover was felt to undermine the possibility of a neighbourly relationship. While some informants living close to people with ID were kept up-to-date, others were not and felt left out.

Mina, opposite neighbour: 'You'll have to check the nametags by the door to see who lives there.'

(...)

Partner Gerrie: 'It's even more annoying when new ones move in; there are people you miss, all of a sudden.'

Coen, next door neighbour: 'Yes, you get the idea you came to live next to a train station.'

Some informants mentioned that their neighbours with ID were not sufficiently visible in the neighbourhood to get familiar with them. First of all, the unique physical features of some care facilities, such as a high fence, or the absence of a garden, porch, or driveway, reduced the opportunities for informants to become familiar with their neighbours with ID. Secondly, some informants did not often see their neighbours with ID around in the neighbourhood and thought they spent more time at activities organised by the care organisation. Lastly, some informants mentioned often seeing their neighbours with ID undertaking activities together in a group (e.g. taking a walk or shopping), and recognised and spoke of the group as a whole rather than of individual neighbours.

Day to day interactions

Generally, when recognizing a neighbour during day to day interactions, informants engaged in certain courtesies. They mentioned to at least greet (wave or nod to) one's neighbours and sometimes engaged in small talk. These interactions occurred during unplanned, spontaneous occasions (e.g. walking the dog, and working around the house), and while outwardly insignificant, were valued.

Day to day interactions with neighbours with ID involved similar activities, but again, some informants mentioned unique characteristics that occasionally seemed to set these experiences apart from interactions with other neighbours. Concerning greeting a familiar face, informants made a distinction between staff and neighbours with ID. While some informants exchanged greetings and small talk with familiar staff, others were unsure whether staff recognised themselves as neighbours, or whether informants themselves were familiar enough with staff to merit a greeting. When informants were ignored by staff they would otherwise greet, it felt as a snub.

Exchanging greetings with familiar neighbours with ID was appreciated, and when none were given or returned, informants were quick to understand.

Nadia, next door neighbour: 'I don't think they recognise us, that they're not interested in us. (...) Indeed, they're just in their own world.'

Small talk with neighbours with ID was sometimes experienced differently than small talk with other neighbours. Informants typified it as rather one-directional in nature; requiring them to adapt to the skills and needs of their neighbours with ID. This did not mean that the interaction was necessarily a negative experience, as some informants said to enjoy the humour and spontaneity of their neighbours.

Marije, next door neighbour: 'You have to reckon with their level of thinking. But other than that. . . You shouldn't have too complicated conversations of course.' (...)

Partner Floris: 'They never have anything unpleasant to say. They're always happy, apparently. (...) They don't have any problems. We have problems, they don't have any problems.'

Others however, felt more apprehensive and were, for example, concerned about mutual understanding, doing and saying the right things, or saw few opportunities for spontaneous small talk.

Gerdien, opposite neighbour: 'I'll be standing there with the dog for a bit, and one is scared, and the other wants to pet him. But then there's, er, well anyway for me it's very hard what my next step should be then.'

Martijn, neighbour down the street: 'Look, when somebody would work in the garden, and you walk by, you'd chat a bit. (...) But that [gardening] is done by the organisation [itself].'

Exchanging favours

While not all informants exchanged favours with their neighbours without ID, most stated that they felt they could, and had in the past, count on their neighbours in need (e.g. an impromptu babysitter, help moving furniture). This potential availability of help was felt by some as providing a safety net. Two conditions seemed to apply, however. First, reciprocity seemed important, as some mentioned to feel apprehensive asking for favours they knew they could not return. Second, favours mostly concerned superficial exchanges (one-time small favours such as help jump-starting a car), giving the impression that overt dependency was discouraged.

Most informants said not to hesitate to offer occasional help to their neighbours with ID should it be asked and some mentioned instances in which help had been exchanged in the past (e.g. sort out mail and water the plants during holidays or provide extra chairs for a party). However, some informants recognised differences in potential favour exchange with neighbours with ID. Firstly, some informants doubted whether they could exchange favours with neighbours with ID, or had low expectations concerning reciprocity. On the one hand, they wondered whether they could ask their neighbours with ID for help, due to their disability, or because they felt insufficiently familiar with staff or residents to legitimately ask. On the other hand, the presence of staff and the recognition of the business-like care around the home discouraged some to offer the typical small favour they would offer to other neighbours. They explained, for instance, that somebody was always at the home to receive packages, or that staff or third parties were

paid to do tasks such as small house or garden maintenance, thus limiting some of the opportunities for offering help.

Secondly, some informants who did offer help to neighbours with ID mentioned their tendency to overstep boundaries. Consequently, they said to actively take measures to prevent incessant calls from their neighbours with ID possibly following an initial offer.

Anna, opposite neighbour: 'Look, and then she came over constantly. And if you'd say (...) "Well, listen, I have visitors," or "We're having dinner, you really should come back later because we're busy." She didn't like that! So at one time, we did warn [staff] once.'

Elise, neighbour down the street: 'There are some residents there, well [name] in any case, they can really start claiming you, that's not always pleasant.'

Lastly, different from neighbours without ID was the often mentioned 'volunteer work' as an advisable approach to helping neighbours with ID (see: Keeping Distance), possibly changing the nature of favour exchange.

Being considerate

Informants mentioned the importance of keeping a neighbour relationship peaceful in relation to quiet domesticity. First, they mentioned the importance of recognising what activities or behaviours would be considered inappropriate and anticipate them (e.g. keep a potentially scary dog on a lead). Second, occasional incivilities (e.g. motorised lawnmowers) were on the whole considered a common occurrence of neighbouring which called for a degree of tolerance. Constant incivilities, however, were to be addressed and settled between neighbours to reconcile the relationship.

Having neighbours with ID had exposed some informants to specific incivilities. For example, some informants mentioned nuisances such as parking issues and increased traffic around the home due to staffing, transport for residents, deliveries, or maintenance. Particular behaviour of neighbours with ID themselves, while not necessarily perceived as dangerous or scary, were felt to be intrusive (peeking through curtains or incessant house calls) or annoying (repetitive speech or cries) by some.

Sometimes, different thought processes or activities were thought to be needed in order to be tolerant or reconcile the relationship. Some informants

philosophised about the necessity to be more tolerant of those essentially not to blame, for others however, this tolerance seemed to be strained.

Jeanne, neighbour down the street: 'Yes, and that's the same as with children. I mean, they cry because they can't talk. But these people also often make sounds because they can't talk. And then, I think, like, that's their communication, isn't it? I think I could tolerate a lot more from them.'

Nadia, next door neighbour: 'The cars that pass here [on the thoroughfare] (...) you won't hear at some point, but that humming [referring to her neighbour with ID on the swing in his garden], or somebody constantly repeating themselves or, er, those are things you're not used to.' (...)

Partner Rens: 'Look and I do understand, what that guy does, he's enjoying himself [humming] on that swing. It's just, well, I do think, I don't understand how staff doesn't see how annoying that may be for the neighbourhood, you know. Well, you can't take that child's, that man's, enjoyment away.'

Efforts to reconcile, by neighbours with ID themselves, but predominantly by staff, were greatly appreciated, reconfirmed a good neighbouring relationship and encouraged future tolerance.

After experiencing excessive noise for a while, Lisa, next door neighbour, received an apology from her neighbours with ID and their staff in the form of home-baked muffins: 'Yes, [it was] very pleasant, because you build up a bit of good-will, you know, build up a buffer (...) And that way, it's a gesture back to you, and I just think it's really nice, like, that they are aware of it.'

The mediating role of staff in resolving problems or complaints was a particular feature of neighbouring with people with ID. The preference to approach neighbours with ID themselves was mentioned once, yet most thought it inadvisable. A few informants compared the help from staff with the responsibility for mediation of parents concerning their children. Concerns were sometimes insufficiently or inappropriately addressed. For example, old habits returned, and noise issues resurfaced, or neighbours felt their voices unheard. Christian, a next door neighbour, describes such an inappropriately

addressed concern, and this seemed to illustrate a breakdown in communication and harmful to their neighbouring relationship.

Christian, next door neighbour, was advised by his neighbours' staff to take his questions or concerns to the relevant department within the care organisation itself: 'You get wedged in a bureaucratic hell. They don't respond, or they don't know, or you have to ask so-and-so, those sorts of things' (...)

Partner Marike: '[After some attempts at addressing the problem] the one thing we heard [from staff] was to not complain anymore. (...) But anyway, the staff you don't see often, they don't live there.'

Interviewer: You wouldn't see staff as your allies?'

Marike: 'No, when we want something, or have to, you really have to try to contact the organisation.'

Keeping distance

Hardly any informant wanted to intensify their interactions with neighbours and seemed to identify a boundary appearing at one's doorstep. Some mentioned the importance of steering clear of other people's affairs to lessen the chance of a committed relationship or conflict. Informants mentioned some exceptional circumstances where neighbouring interactions were permitted to be prolonged or intensified. Examples such as meeting others during more formal occasions (e.g. christenings, neighbourhood parties, or committee meetings), or having developed a friendship, were mentioned.

For some informants, ensuring an appropriate distance from neighbours with ID required extra efforts. As discussed earlier, some informants noticed a tendency of some of their neighbours with ID to overstep boundaries and consequently made efforts to not get too involved or create expectations. Other informants, not necessarily having experienced this themselves, sometimes anticipated it.

Joyce, opposite neighbour: 'Well, we had one once, who said: "can I come in for a bit?" But at one point a member of staff said: "you better not do that, once they come around, you won't be able to get rid of them again." Then one would have to hurt people, like, "you're not allowed over again" or something like that. So that's why I didn't look for any contact anymore.'

Some informants had difficulty thinking of mutually agreeable opportunities for extended contact with neighbours with ID. While coffee visits, parties and open days were considered good opportunities to get to know one another, get information or satisfy one's curiosity, subsequent visits or formal occasions were not always considered desirable. Firstly, inviting neighbours with ID over seemed something that required extra effort.

Willem, opposite neighbour, remembers having coffee with his neighbour with ID who was invited over by his wife: '[He would tell] a couple of times the same story (...) Well, it's not annoying per se, but for me it's a little hard to, say, to keep going. Because what should you say, what should you ask? It's up to you to keep the conversation going. (...) Perhaps a bit of a job.'

Elise, neighbour down the street: 'You'd have the feeling that you'd have to watch them a little more. Not to make sure they might do something, but to see if they're, well, comfortable.'

Secondly, as some informants saw their neighbours with ID often as a group, some wondered whether individual interactions were possible or whether these would necessarily involve all residents; something which would make a visit more formal and less pleasant. Lastly, some informants were apprehensive of extended social contact, especially when arranged formally, as it may imply an interest in involvement beyond the informants' intention.

Floris, next door neighbour: 'It has to happen spontaneously, friendly interaction. Otherwise, it doesn't feel good, like an obligation. (...) So, for god's sake don't force anything.'

The motivation to engage in more intensive contact with one's neighbour with ID seemed more strongly associated with a felt duty to give support to those perceived as disadvantaged, rather than stemming from a personal desire for a social relationship. Formalising a neighbour relationship in terms of volunteering then seemed something that many informants saw as especially relevant for people with ID.

Gerdien, opposite neighbour: 'And should I get the question, like, gee, would you like to invite someone, socially, I would certainly,

but more from a societal awareness than that I would like contact myself (...) I just live here, it's not my job, so there's a boundary there. (...) I don't want extra obligations'.

Interviewer: 'You would see this as a job?'

Gerdien: 'Yes, that statement does apply, that I quickly, because I don't feel a social connection so, instantly, the feeling of a job, help, yeah, volunteering, that sort of thing, that comes up.'

Elisabeth, neighbour down the street: 'I had that little note [asking for volunteers] here for ages and was hesitating so much, but again, in our church we have people like him too, of course. So yeah, that's where I put my efforts.'

Generally, however, informants were reluctant to be a volunteer. Time constraints, expecting too much responsibility and commitment, and worries about one's competence discouraged most informants. This implied commitment was seen to be something that goes beyond normal neighbouring and needed a different motivation than merely being a good neighbour.

General expectations of neighbouring with people with ID

Nearly all informants supported having people with ID in their neighbourhood, for various reasons (e.g. the positive learning experience, humanitarian or philosophical considerations). Informants differed, however, in their estimations of responsible neighbouring they could expect from their neighbours with ID. On the one hand, some informants experienced no differences in neighbouring with neighbours with or without ID, and had similar expectations about both.

Floris, next door neighbour: 'Ultimately, with these people, one makes a distinction too, and that is something I don't. . . It doesn't feel good to me (...) It's this study too, isn't it? Like "how do they function [sic] in this neighbourhood". No, how do we function, for them? Turn it around. Because we're the ones making a distinction (...) To me, it leaves a bitter aftertaste, like, yeah, it's a little discriminating. I don't know. I find it normal.'

On the other hand, some informants experienced so many differences that they doubted whether their neighbours with ID could be considered

neighbours, or were more like a separate, closed community within their neighbourhood, possibly complicating their neighbouring expectations.

Christian, next door neighbour, talking about the use of two conjoined semi-detached houses as a single home: 'And now, to me, it's not even a home anymore, they've turned it into an institution again. They've build an annex. (...)You think you've come to live in a neighbourhood, where, how shall we put it, not being discriminating, normal people live'. (...)

Partner Marike: 'Yes, this is different though, from when you'd have families living there'.

Discussion

In the present study, neighbours of people with ID were invited to talk about their experiences with neighbouring in general and with neighbouring involving people with ID living in small scale care facilities on their street in particular. Content analysis revealed that neighbouring with people with ID sometimes appeared to have unique features. It is possible to categorise these features into two broad categories. First, the institutional nature of care homes for people with ID, even in those appearing a regular home, means that these homes still carry features of institutions which change the dynamics of neighbouring. This business-like image manifested itself, for example, in the manner in which care was organised (e.g. maintenance and construction of the home), in the formality with which neighbours were, sometimes, approached (e.g. open days and asking for volunteers), and the relative invisibility of residents on occasion. This seems to correspond with previous research that has also revealed that people make a distinction between attitudes towards a home for people with ID and attitudes to individual residents (Hudson-Allez & Barrett, 1996; Schwartz & Rabinovitz, 2001). Moreover, the observation that changing the living arrangements of people with ID from institutional to community care does not necessarily mean that all the habits of the old institution are shed (Overkamp, 2002; Van Alphen et al., 2009) may therefore also refer to the habits in interacting with neighbours. In this case, the degree to which neighbours may perceive the care home as a business may influence their interaction expectations.

Second, possibly depending on the level of disability, neighbours of a person with ID may have to change their expectations about neighbouring, or be more tolerant of unusual behaviours or noises. These neighbours may also

be inclined to think that their neighbours with ID require more interpersonal involvement or care than they are willing to provide. Many informants in this study seem to prefer to arrange this formally, which may be expected in a society that often formalizes care (Schwartz, 1997). Neighbours, then, may experience ambivalence when they reflect on desirable interactions with their neighbours with ID, trying to engage in what they perceive as regular neighbouring, while at the same time taking into account the special needs and challenges their neighbours with ID may pose on them, and avoiding becoming more involved than intended.

It should be noted that these two features do not imply that informants necessarily made negative evaluations of neighbouring with people with ID. The degree to which informants may think they apply, however, may make neighbouring with people with ID a different experience, possibly requiring them to adapt their expectations and behaviour.

Study limitations

While this study gave some insight into the lived experience of neighbours of people with ID, and how neighbouring principles may be upheld or violated in situations where one is a neighbour of people with ID, this study has some limitations. Firstly, the low response rate may suggest a selection bias. It is plausible that only people with a vested interest in the outcome of the topic under study participated. However, the diversity of experiences, referring to both positive and negative aspects of neighbouring, suggests that self-selection may have been less likely here.

Nevertheless, one should be careful not to generalize the present findings. The sample largely comprised a female, middle-aged, married, and middle-class population, living in relatively quiet suburban areas. Experiences of people in metropolitan and ethnically diverse areas may be different.

Theoretical and practical implications for social integration

This study has generated a picture of everyday interactions in a neighbourhood in which people with and without ID live. Successful neighbouring requires that all parties involved are concerned about each others' expectations and desires with respect to neighbouring. Hence, in addition to inquiring about the specific perceptions and expectations of neighbours of people with ID, it is also important to study the views of the latter with respect to neighbouring. We have already made a start with this (Van Alphen et al., 2009). In particular, we found that people with ID have

similar desires with respect to neighbouring as the presently interviewed neighbours. However, they also mention particularities, such as insecurity in meeting unfamiliar others (sometimes related to their disability) and the mediating role of staff. These features have been found in other studies into social integration of people with ID (Abbott & McConkey, 2006) and indicate a need to understand more of the delicate balance between too much interference and needed support from staff or a care organisation.

In light of this, the results of the present study may have several implications for care organisations or researchers concerned with the successful social integration of people with ID. First, familiarisation with particular neighbouring customs in a locality may be necessary for a better understanding of how neighbours with and without ID can interact to mutual satisfaction. Outwardly appearing as a regular house and interacting with neighbours in small and mundane neighbourhood exchanges may help people with and without ID in interacting as individual neighbours rather than as two separate groups.

However, given the important role which informants gave to staff in mediating neighbouring between their clients and neighbours, an organisation may need to recognise its responsibility in acting as a good neighbour too (cf. Cook, 1998) and recognise when formality, support or intervention is needed in order to smooth conflicts or help those who are struggling or uncomfortable in interactions.

Finally, staff may help residents and neighbours in identifying possibilities to engage in mutually acceptable forms of neighbouring, taking into account the ambivalence, capabilities and insecurities of both (cf. Van Alphen et al., 2009). This may call for an awareness of the tensions between supporting people with ID making individual choices about how they choose to interact with neighbours, and supporting the needs other neighbours without ID may have in interactions with the former.

The tensions between supporting the needs and rights of people with ID whilst guarding the needs of others are also observed in other areas of integration of people with ID, such as education mainstreaming (Clegg et al., 2008). Research and policies concerned with (social) integration of groups with special needs may benefit from taking an approach that does justice to the complex wishes, insecurities and capabilities of all involved during interactions with each other, rather than taking an approach that tests mere acceptance or rejection of the presence of these groups in various (social) contexts.

Chapter 6

Social Integration of People with Intellectual Disability: Insights from a Social-Psychological Research Perspective

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Abstract

Social integration of people with intellectual disability (ID) moving into regular neighbourhoods tends to be studied and evaluated without detailed knowledge about the social-psychological aspects of everyday interaction between neighbours with and without ID. The goal of the present paper is to show how the authors' social-psychological research programme may contribute to this field of inquiry.

The different ways in which societies respond to features and behaviours that may be perceived as deviant are theoretically analysed. Results of empirical studies are reported to clarify how social responses to people with ID are special in terms of perceptions, emotions, and interaction desires of people with and without ID during a pre-contact and contact phase.

On the basis of the theoretical analysis, it is concluded that regular neighbouring in modern Western society often takes the form of benevolent tolerance, rather than stigmatisation and prejudice. However, empirical studies reveal that, prior to getting people with ID as new neighbours, prospective neighbours without ID experience a specific pattern of emotions that are associated with specific desires (e.g. with respect to information supply or a caring relationship). These anticipatory reactions are dependent on the expected size of the group moving in and on the severity of intellectual disability. Furthermore, while actually engaging in neighbouring, neighbours with and without ID appear to have experiences related to behaviour of residents, staff, and features of housing facilities that are perceived as (in) congruent with regular neighbouring.

It is concluded that interpersonal relationships between neighbours with and without ID should not be simplified in terms of attitudes that would be primarily prejudiced/stigmatising versus entirely accepting. Rather, our studies paint a more complex picture of sometimes ambivalent thoughts, feelings, and interaction needs that all should be taken into account to make social integration a success.

Introduction

People with intellectual disability (ID) are increasingly expected to relocate from traditional institutional care to 'regular' neighbourhood housing facilities and to socially integrate in these neighbourhoods. Unavoidably, those involved in the process of relocation such as policy makers and care providers make certain assumptions about the nature of modern neighbourhoods, relationships among neighbours, and the psychological processes underlying people's reactions to intellectual disability. This paper examines to what extent these assumptions are valid and how they influence the effectiveness of attempts to improve social integration. Reporting results of our own research programme, we will show that a social-psychological perspective proves some of these assumptions to be too general and sometimes wrong, and may contribute to the development of effective social integration strategies¹.

¹ Due to space limitations, we simplify this presentation with respect to the following issues. First, we do not discuss different conceptions of, and political controversies surrounding, social integration and related issues such as normalisation and the meaning of "disability" (for discussions, see Dowse, 2009; Myers et al., 1998; Reinders, 2002; Simpson, 1998; Vehmas, 2004). Instead, we associate social integration primarily with engaging in social relationships that are experienced by both parties as satisfactory and pleasant; against the background of established practices and general expectations. As will become evident, what is seen as a desirable social relationship may not be the same in an individualistic, tolerant, and relatively uninvolved Western neighbourhood and in a small communal group or family. Second, we primarily focus on people with ID living in group homes that were established by institutions for purposes of deinstitutionalisation. It should be noted, however, that there are other kinds of care facilities located in regular neighbourhoods (e.g. those initiated by family members and making use of individualised funding) that are equally faced with problems of social integration addressed in the present paper. Third, we do not consider variability in intellectual disabilities, only making a rough distinction between mild and severe types. Fourth, our approach is primarily descriptive and explanatory, with an emphasis on social-psychological processes and mechanisms, yet in a selective way. In particular, in our research programme we have found it more useful to analyse relationships between neighbours in terms of social control mechanisms, different types of perceived deviance, and specific appraisals and emotions, rather than using broader social-psychological concepts such as social identity, intergroup relations, and stereotyping (for reviews on these topics, see Hewstone et al., 2002; Pettigrew, 1998; Yzerbyt & Demoulin, 2010), or analysing social integration in terms of political power and rights (see Shakespeare, 2006, for a comprehensive discussion). Note that our use of the term deviance recognises that conditions and behaviours that are evaluated as undesirable have both objective and subjective or more derived aspects. The former aspects imply that in any social group members are capable of distinguishing between universal types of deviance such as crime and illness, and that certain objective aspects of these behaviours or conditions help to make these distinctions. The latter aspects refer to relatively unique cultural practices in assigning specific conditions and behaviours to different types, and to effects of labelling sometimes termed secondary deviance (for reflections on the term deviance, as well as the literature on labelling, see Dijker & Koomen, 2007; Goode, 2003).

To illustrate the urgency of the present inquiry, consider the assumption that prospective neighbours initially tend to react with irrational prejudice, opposition, or not-in-my-backyard responses to the planned location of a facility for people with special needs (Dear, 1992; Jason et al., 2008), but after the realisation of the facility and as time passes gradually reduce their opposition and even come to accept their new neighbours (Arens, 1993; Cook, 1997; Hudson-Allez & Barrett, 1996; Lubin, Schwartz, Zigman & Janicki, 1982). Sometimes, it is also assumed that the latter change occurs because people have come to realise, on the basis of new information or more extensive contact, that their initial responses were ill-founded. These assumptions would imply that it is not only legitimate (after all, people tend to respond irrationally and impulsively on first impressions) but also safe to ignore initial objections and to refrain from inquiring about their specific contents (Zippay, 2007). Indeed, it sometimes seems to be assumed that social integration can be quite easily realised since many modern neighbourhoods are basically tolerant and accepting, despite some initial prejudice.

As we explain in the next section, these assumptions are based on insufficient knowledge about the nature of social groups and neighbourhoods, and the manner in which they normally attempt to control conditions and behaviours that they perceive as undesirable or deviant. In addition, there seems little awareness of the specific influences that intellectual disability in particular may have on other people's perceptions, emotions, and desires for interaction. Rather than being motivated by prejudice or hostile attitudes, concerns and irritations may be based on certain emotional implications and expected interaction difficulties associated with perceptions that are not entirely unrealistic. Moreover, reduced visibility of blatant negative responses may imply active suppression of these responses rather than willingness to engage in normal neighbouring. Even when neighbours can be said to be tolerant, one has to ask to what extent mere tolerance would be beneficial to the well-being and quality of life of people with ID living in regular neighbourhoods.

During the last two decades, interest in studying and evaluating social integration of people with ID in terms of social reactions of (prospective) neighbours has increased (Hudson-Allez & Barrett, 1996; Pittock & Potts, 1988; Robertson et al., 2005; Schwartz & Rabinovitz, 2001). However, these reactions tend to be primarily framed in terms of global attitudes for or against the arrival or presence of housing facilities (and the manner in which these attitudes can be changed), rather than in terms of specific and mutual perceptions, emotions, and interaction needs; the focus of the present analysis.

This paper is organised as follows. In the next section, we examine how social groups generally respond to different conditions and behaviours that are perceived as deviant, especially in the context of relationships among neighbours in modern Western society. This is the general background against which responses to neighbours with ID should be examined. In a subsequent section, we ask what makes neighbouring with people with ID special and use results of our own research programme to answer this question. This is followed by a section in which we first examine the validity of certain assumptions about the psychological aspects of social integration of people with ID, and then outline the implications that our research programme may have for the development of successful social integration strategies.

Psychological mechanisms underlying social responses to perceived deviance

Social groups and societies employ different strategies to prevent, reduce, and deal with behaviours and properties of its members that are perceived as undesirable or deviant. These social control strategies are motivated by general psychological mechanisms. To uncover these mechanisms, Dijker and Koomen (2007) distinguish between repair, stigmatisation, and tolerance as major social control strategies.

Repair

Repair refers to the most basic form of social control and is primarily aimed at preventing and reducing deviance while at the same time trying to keep the deviant group member in the group. Repair is characteristic for relatively small and communal social groups and is motivated by a set of emotions that are triggered by the perception and appraisal of different types of deviance. For example, behaviours that pose a threat to the well-being of other group members (e.g. theft, aggression) tend to evoke anger and a desire to punish the deviant individual. These responses, in turn, produce shame or guilt in perpetrators, motivating them to change their behaviour, subsequently resulting in rehabilitation and forgiveness. The repair of disturbed social relationships has succeeded if normal group functioning has been restored.

More passive forms of perceived deviance such as physical illness or dependency are also the targets of repair, yet on the basis of a quite different emotion or motivational state: Sympathy and a desire to nurture and heal the deviant person, and ideally resulting in recovery and re-integration into society.

A crucial factor that moderates reactions to deviance is perceived responsibility (cf. Weiner et al., 1988). The above mentioned examples of active and passive deviance assume that the deviant individual is responsible for norm-violating behaviour and lacked responsibility for getting ill, respectively. However, in the former case, one can also imagine that threatening behaviour is unintentional, impulsive, and hence primarily fear-arousing; not evoking punishment but self-protection such as permanent imprisonment or hospitalisation of the deviant individual. Furthermore, illness and dependency may also be associated with a high level of responsibility and hence angry responses because, for example, ill individuals do not appear to care enough about their own health and seem to parasitise on others' kindness (Dijker & Koomen, 2003). Indeed, although the ill person is allowed to refrain from normal social duties and to ask for help, the 'sick role' (Parsons, 1975) requires certain responsibilities such as a motivation and effort to get well as soon as possible.

The above distinctions between different types of deviant conditions allow us to get a better grip on the social and emotional responses that intellectual disability tends to evoke in a community. We know that, relative to other deviant conditions, intellectual disability is perceived as a complex condition that is difficult to respond to in terms of repair (Dijker et al., 1998; Dijker et al., 2000). In particular, the condition has both aspects of passive (e.g. physical handicap, dependency) and active deviance (e.g. strange, norm-violating, or threatening behaviour or threatening facial appearance), combined with a perceived lack of foresight, responsibility or intelligence; hence a condition that is likely to arouse a mixture of sympathy, fear, and irritation in others. The facial appearance and behaviours of some people with ID also tend to spontaneously evoke positive emotions in perceivers such as tenderness and joy, similar to the emotions that are aroused by vulnerable and 'cute' infants, and that motivate caring and protective behaviour (Dijker et al., 2000).

How a community deals with a deviant condition such as intellectual disability that is ambiguous and not 'repairable' (due to its permanent character) depends on both the severity of the condition and certain social characteristics. For example, Edgerton (1970) and Reynolds Whyte (1998) describe how in small and 'primitive' societies, people with ID were given useful roles (e.g. attending livestock), ensuring their high visibility and social integration. They also mention examples indicating that in the absence of certain useful competencies, people with ID may still engage in limited reciprocity by, for example, presenting caring others with contagious and enjoyable expressions of happiness (see also Taylor & Bogdan, 1989). Other

research suggests, however, that people with ID tend to motivate others to establish relationships that are largely asymmetric and nonreciprocal, primarily based on helping and nurturance (Fishbein, 2002; Webster & Carter, 2007).

Stigmatisation

As described, repair has the appearance of a rather benevolent social process, consisting of a mixture of, on the one hand, aggressive or punitive, and on the other, 'soft' or nurturing responses. Unfortunately, social control can also take the form of stigmatisation; a form of responding to deviance that is not intended to socially include but exclude the deviant individual, considering the deviant condition not as a changeable or repairable but as a permanent and essential feature of the individual's character. While stigmatisation may also be based on emotions that are involved in repair (e.g. anger and fear), it is distinctively associated with public denigration of the individual, expressed in contempt, Schadenfreude, and name calling, and therefore likely to result in shame, low self-esteem, and avoidance of social contact (Crocker, Major & Steele, 1998; Heatherton, Kleck, Hebl & Hull, 2000). Stigmatisation may occur for different and complementary reasons such as the assumed permanence, severity, and threat of a deviant condition (e.g. previous convictions, child abuse, contagious and lethal disease); lack of behavioural repair options; size of the social group or society (in a large society, individuals expect relatively little commitment to change or adapt behaviour); and the active employment or even creation of deviant conditions by those in power in order to control or get rid of certain groups, and allowing the general public to displace its frustration by means of scapegoating and public shaming (for discussions of these different possibilities, see Dijkster & Koomen, 2007).

Tolerance

Finally, a third form of social control which Dijkster and Koomen (2007) distinguish is tolerance which they believe characterises social control in modern and individualistic Western societies. While in repair and stigmatisation, people directly respond to perceived deviance, in tolerance people notice the deviant condition yet actively try to suppress the negative feelings aroused by it or minimise exposure to it by 'looking the other way' or by avoiding contact. Characteristic psychological aspects of tolerance are self-control, attempts to mask negative feelings by displaying exaggerated kindness, tension, and superficial social contact, which may appear cold and

unfriendly. Such a mode of responding, however, is only possible in a society in which social control is formally taken care off by a wide variety of specialised institutions engaged in, for example, law enforcement and punishment (police, judicial system, prisons), healing (e.g. medicine, therapy), long-term care, and rehabilitation. It also seems clear that tolerance is difficult to realise or maintain under conditions in which motivational systems responsible for fear and aggression are strongly activated (e.g. in times of scarcity or war).

Of particular relevance for the present paper is to examine what social control looks like in neighbourhoods in modern Western society. Although some neighbourhoods may resemble small communities in which repair processes can take place in the case of perceived deviance, most modern towns and cities probably use tolerance as a major strategy to respond to deviance. In the case of relationships between neighbours (for general reviews of neighbouring, see Bulmer, 1986; Forrest & Kearns, 2001; Unger & Wandersman, 1985), tolerance will be particularly challenging when prospective neighbours are associated with relatively permanent deviant conditions and behaviours. In particular, tolerance may transform into blatant stigmatisation when confidence in authorities with respect to formal social control has declined and neighbours experience little control over the behaviour of their neighbours. In any case, neighbouring in modern Western society demands a lot from neighbours; a particular psychological competence to balance a tolerant but distant attitude with benevolent interest in each others' needs and readiness for reciprocal exchange of favours and goods. We now examine what this implies for the quality of relationships when people with and without ID engage in neighbouring.

What is considered special about people with ID as neighbours?

In our own research programme, we set out to systematically examine how people respond to individuals with ID in the context of neighbouring, distinguishing between a phase during which people anticipate to get people with ID as new neighbours (Van Alphen, Dijker, Bos, Borne & Curfs, 2011a, 2011b) and a phase during which people with and without ID actually interact as neighbours (Van Alphen et al., 2010). With respect to the latter stage, we have also examined how people with ID themselves experience the social aspects of living in regular neighbourhoods (Van Alphen et al., 2009). In general, we have found that, at each stage, and in light of a desire for tolerant neighbouring, the particular image of people with ID and characteristics of the

care facility and its supporting staff call for a set of specific emotions and desires among (prospective) neighbours without ID.

Expecting to have people with ID as new neighbours

In two studies, using a nationwide online panel, we asked a representative sample of the Dutch population to imagine that their current next door neighbours would move out and that their place would be taken by members of a particular social group (for details about the sampling procedure, sample characteristics, design, and measures, see Van Alphen et al., 2011a, 2011b). Participants were additionally informed that their new neighbours would occasionally receive professional assistance. In one study (Van Alphen et al., 2011a), respondents were randomly assigned to four members of one of five different social groups associated with a deviant condition – people with mild or severe intellectual disability, economic refugees, elderly people, and young offenders – and asked to what extent they would accept them as next door neighbours, and to report traits thought to be characteristic for these groups, felt emotional reactions, and preferred relationships with residents as well as staff. These groups were selected to represent clear differences on the active-passive and responsibility dimensions discussed earlier and hence to reveal the specific emotions, desires, and challenges associated with intellectually disability during a pre-contact phase.

We found that young offenders were least, and elderly persons and people with mild intellectual disability, most accepted as new next door neighbours. Complementarily, young offenders were seen as most, and elderly people and people with mild ID as least dangerous and anxiety arousing. The latter two groups were also seen as sociable, vulnerable, and sympathy-arousing. (While economic refugees were less accepted as neighbours than elderly or intellectually disabled people, they were met with greater acceptance than young offenders.) An ambivalent way of responding to people with severe intellectual disability was suggested by relatively strong anxiety and anger, despite relatively strong sympathy.

Because we also measured frequency of previous contact with members of the different groups, we were able to examine the relative influence of previous contact and emotions aroused during anticipation of future contact. We found that the emotion-evoking potential of the studied social groups exerted a much stronger influence on acceptance of future contact than frequency of previous contact with these groups. Apparently, even people who report a high frequency of previous intergroup contact may base their decisions to engage in future contact on emotions typically aroused by the particular group involved.

Another important result of this study was that we could establish specific behavioural implications of the emotions that were aroused during anticipation of contact with the different neighbours. For example, we found that the more anxiety was experienced while anticipating contact with the new neighbours, the more respondents preferred a prior opportunity to vote against their arrival or to have a voice in determining which specific individuals should move in next door. Anxiety also was related to a preference for hierarchical relationships with the neighbours, with respondents playing a dominant role, and less willingness to engage in reciprocal relationships with them. However, anxiety also implied a greater interest in receiving additional information about the group moving in. Aroused anger had similar behavioural consequences, yet was unrelated to a desire for information and was associated with a preference for minimal or superficial contact. Finally, felt sympathy appeared to have primarily pro-social implications, as it was positively correlated with a desire for a caring as well as a reciprocal relationship.

Employing a similar research method, a second study examined to what extent anticipatory responses to new neighbours with ID are dependent on severity of ID and group size (Van Alphen et al., 2011); two factors associated with perceived threat and hence likely to be important for policy makers and staff in predicting opposition from neighbours without ID. In particular, we presented participants either with prospective neighbours with mild or severe ID, explicitly stating that level of intelligence was comparable to that of an eleven-year old or two-year old, respectively; yet that the neighbours with mild ID did not suffer from physical problems, whereas the group with severe ID was associated with both physical and behavioural problems. Group size was varied by presenting participants with a group of four persons (representing the size of a regular household) or twelve persons (a small institution).

Results of this study indicated that severity of disability and group size independently influenced social acceptance and a variety of emotional and behavioural responses. In particular, it was found that a large group with severe disability aroused the strongest, and a small group with mild disability the weakest, negative responses. Small groups with a severe disability and large groups with a mild disability aroused similar and intermediate negative responses. Importantly, a similar ordering of responses was visible on desired behaviours that may influence the success of attempts at social integration, namely: Desire for preparation (strongest for the large group with severe ID), solving problems with staff rather than residents (strongest for the large group

with severe ID), and willingness to be a volunteer (strongest for the small group with mild ID).

People with and without ID living as next door neighbours

We performed two qualitative interview studies to examine how people with and without ID experience each other as neighbours, with the former living in small scale care facilities run by a care organisation and the latter being their next door neighbours. In the study addressing people without ID (Van Alphen et al., 2010), we first inquired about respondents' everyday experiences of, and expectancies about, neighbouring in general, and subsequently asked questions about their contact with their next door neighbours with ID. This questioning strategy allowed us both to uncover general themes present in respondents' conceptions of regular or "normal" neighbouring and to let respondents reflect on the particular ways in which neighbouring with people with ID appears congruent or incongruent with these general themes and expectations (details about sampling procedure, data coding and interpretation are presented in Van Alphen et al., 2010).

Consistent with our theoretical analysis of tolerant neighbouring in Western society, a number of themes associated with neighbouring in general emerged which can be summarised in the following way. Neighbours generally are expected to keep a balance between, on the one hand, mutual recognition and politeness, showing a benevolent interest in each others' needs, and readiness to engage in reciprocal exchange of goods and services; and, on the other hand, keeping their appropriate distance and respecting each others' privacy and individual characteristics, and hence not getting over-involved in each others' lives. In analysing reports on what makes neighbouring with people with ID special, we found little evidence of general stigmatisation of people with ID as a social category, but detailed accounts of the manner in which behaviour of both residents and staff of the care facility was perceived as either congruent or incongruent with principles of normal neighbouring.

Examples of incongruence included staff showing lack of recognition, politeness (failure to greet), or interest; staff preventing personal and reciprocal contact between residents with neighbours; staff not informing neighbours about individual residents moving in or out; physical aspects of the home preventing normal neighbouring (e.g. a high fence, absence of front garden, porch or driveway); other business-like features such as staff turn-over; and formalisation of contact with the neighbourhood through 'open days' and employment of volunteers engaging in asymmetric or supporting relationships with residents. Note that the concept of a 'volunteer' was associated with

ambivalence in our respondents as it implied that one either could have a highly involved but asymmetrical relationship with residents with ID or hardly a relationship at all (not even a relationship based on tolerance). With respect to residents with ID themselves, neighbours without ID mentioned certain annoying or threatening behaviours for which residents were expected not to be accountable; residents expecting too much emotional involvement rather than normal and relatively distant forms of neighbourly contact; and residents acting as a group rather than as (approachable) individuals. While these examples all sound negative, they were not always seen as problematic but rather mentioned as matter of fact differences.

Yet, our respondents also provided evidence for congruence with normal neighbouring or potential ways to improve its quality. Thus mentioned were examples of active involvement of both residents and staff in maintaining reciprocity (in the sense of returning favours), and active mediation by staff in the case of annoyances.

Interestingly, the study in which we interviewed residents of care facilities themselves about experiences with neighbouring (for details about sampling procedure and content analysis, see Van Alphen et al., 2009) confirmed and complemented the reports provided by neighbours without ID. For example, staff was reported to both facilitate and limit social interaction with neighbours (similar to findings reported by Abbott & McConkey, 2006), with social activities often taking place at the grounds of the old institution, involving other people with ID, and without using community facilities. Importantly, these reports also revealed in what respect neighbouring may have a different meaning and be less important for residents with ID than for neighbours without ID. For example, in talking about relations with neighbours, people with ID tended to confuse neighbours with volunteers or particular friends in the neighbourhood, reported interaction anxiety in neighbouring in general, but attached great importance to the presence of agreeable housemates and a home that could provide safety.

Implications for social integration

To better understand opportunities for social integration, the approach we applied suggests that it is useful to distinguish between different forms of social control, different types of social deviance, and different underlying psychological mechanisms. For example, policy makers involved in de-institutionalisation and social integration in modern Western societies, often should expect tolerant and well-intentioned people to be the new neighbours

of people with ID. But it is crucial to interpret the concept of tolerance in the right manner. For one thing, it does not mean that people will not be negatively affected by the deviant conditions with which they associate other individuals. Indeed, our research has suggested that a wide variety of emotions are associated with the images or representations that people have with respect to different deviant conditions. Importantly, inconsistent with the immensely influential contact hypothesis (for reviews, see Brown & Hewstone, 2005; Pettigrew & Tropp, 2006), these emotions continue to determine readiness for future contact even in those individuals with high levels of previous contact (Van Alphen et al., 2011).

For another, the concept of tolerance implies that successful suppression and handling of negative feelings may break down when tested to the limits, sometimes resulting in repair or stigmatisation. Both implications of the concept of tolerance further mean that it would be unwise to ignore specific perceptions, emotions, and concerns, and interpret the absence of blatant negative reactions as evidence for successful integration. We believe that policy makers are insufficiently aware of these complexities, and may be too judgmental about people's reactions to intellectual disability. This may unwittingly encourage previously tolerant individuals to engage in stigmatisation.

Although we have hardly begun to study what actually happens when people with and without ID anticipate to become next door neighbours and actually engage in neighbouring, and how a pre-contact and contact phase relate to each other, we tentatively would like to highlight several specific implications of our four studies. Our studies first suggest that it is necessary to realistically examine to what extent the residents of a home for people with ID located in a regular neighbourhood can be considered as regular neighbours. As reported by both the neighbours with and without ID in our studies, the behaviour of supporting staff may contradict principles of normal neighbouring. Perhaps, training staff to behave more like real neighbours may prevent these incongruencies.

A more problematic point for social integration is the fact that the individuals with and without ID that we interviewed do not seem to hold the same assumptions and expectations about what it means to engage in neighbouring. In particular, while the former may attach great importance to a warm and safe environment with only a few friends or volunteers nearby, the latter distinguish between friends and neighbours and expect most neighbours to be competent in balancing benevolence and distance. The question thus arises whether, under these circumstances, we could expect people with ID to

engage in normal neighbouring at all; and to what extent they benefit from being forced to do so (Myers et al., 1998). To address the latter aspect, one should systematically relate quality of life measures (Brown & Brown, 2005; Schalock et al., 2002) to different aspects of living in regular neighbourhoods.

Taken together, our studies also have shown how important it is to carefully attend to what goes on in people's minds both before and during interaction as neighbours, and to take into account that emotions experienced at the pre-contact stage may determine responses and interaction at the contact stage. For example, we found that emotions experienced during anticipation of contact (e.g. anxiety, sympathy) were correlated with particular desires (e.g. need for information or desire to care for neighbours) that staff may want to satisfy. Although only future research employing longitudinal designs can appropriately address this issue, it seems safe to assume that not respecting these desires may have repercussions at later stages of contact (Zippay, 1997). Furthermore, if more direct contact between neighbours with and without ID is desired, staff may have to take into account that neighbours without ID sometimes prefer to approach staff rather than residents in case of problems. This suggests that staff should be capable of varying and adapting their mediating role in order to encourage more direct contact with residents.

Finally, consider how knowledge about particular positive emotions may indicate certain opportunities to improve contact between neighbours with and without ID. At first sight, one may condemn people's tendency to experience tenderness or compassion towards people with ID as such feelings would imply an asymmetrical relationship and lack of respect. However, respect and admiration usually are aroused when people show evidence of a particular competence (Sennett, 2003). For those perceived as incapable of acquiring competencies necessary in the context of neighbouring, tenderness and care seem highly desirable feelings that deserve to be nurtured.

Conclusions

In our view, social integration of people with ID has succeeded when interaction between neighbours with and without ID answers to mutual needs, and is adapted to principles of social control that are normally observed in a particular society or neighbourhood. This implies that the well-being and quality of life of people with ID are best served with a realistic and detailed assessment of threats and opportunities with respect to social integration. We have discussed different threats and opportunities that policy makers and staff may take into account to further improve the quality of neighbouring.

Obviously, the effectiveness of our suggestions has to be tested in future research. What we hope to have contributed to this emerging research area is the awareness that for social integration to succeed, it is important to take all parties involved seriously, and to refrain from judging people without ID primarily in terms of prejudiced or stigmatising tendencies.

Chapter 7

General Discussion

General discussion

With the intent to improve overall quality of life of people with intellectual disabilities (ID), more countries have made a declaration to stimulate the provision of care in small scale housing facilities in regular neighbourhoods ('Community Care') rather than in large scale institutions (World Health Organisation, 2010). High on the agenda of policy makers and researchers involved in community care policies are the social relationships that people with ID have with other people in society, as they are an important determinant of their well-being and quality of life (Emerson & McVilly, 2004; Kampert & Goreczny, 2007). These social relationships of people with ID do not only involve voluntary relationships with people they choose, such as friends, and to a lesser degree perhaps family members, housemates, volunteers and staff, but also involve contact with members of society one cannot choose, such as neighbours. Not only are neighbours important actors in the physical integration of people with ID moving into neighbourhoods, having good neighbouring relationships is also related to social integration and affects ones health, well-being, sense of safety and connectedness (Beaudoin, 2009; Farrell et al., 2004; Riger & Lavrakas, 1981; Ross & Jang, 2000; Walker & Hiller, 2007; Weden et al., 2008).

In neighbourhood social integration literature (both popular and scientific), assumptions often seem to be made about the nature of social interactions between neighbours with and without ID and their presumed mutual needs. In our studies, rather than approaching neighbourhood social integration from assumed needs or norms, the focus is on interpersonal contact from a social psychological perspective: detailed attention has been given to the thoughts and behaviours of neighbours with and without ID at a pre-contact and contact stage. From our research, we came to a preliminary understanding of the mutual responses to interpersonal contact between neighbours with and without ID, and what may be the underlying psychological mechanisms responsible for these responses. Much work still needs to be done to unravel the specific and complex relations between these thoughts, emotions and interaction needs, and their causes. However, it may be possible to draw some preliminary conclusions and speculate about the practical implications for care organisations involved in neighbourhood social integration.

In this chapter, we first briefly summarise the results of our empirical studies, outline the different strengths and limitations of these studies and contemplate directions for future research into social integration of people with ID. Then the practical implications of our findings are discussed; outlining

opportunities for care organisations for improving the quality of life of people with ID through improving their neighbourhood social integration.

Main results

In this study, we have come to understand more about the psychological processes involved in responding to interpersonal contact with people with ID. Below the main results of research into anticipated and actual contact between people with and without ID will be presented. Firstly, in studying responses to anticipated contact with people with ID, we have found that emotional responses are associated with different interaction needs, which is relevant for understanding possible motivations for social rejection at a pre-contact stage. Additionally, in studying actual interpersonal contact experiences, we have found that neighbouring between people with and without ID cannot be seen in a vacuum, and the specific context of baseline neighbouring needs to be taken into account. This means that one should be aware of where and how neighbouring needs of people with and without ID may differ, in order to make an attempt at matching them.

Anticipating interpersonal contact

In line with our expectations, we found that neighbours anticipating interpersonal contact with people with ID were motivated by their emotions in either rejecting or accepting their presence in their neighbourhood (see chapter 2 and 3). These aroused emotions were different from emotions towards other social groups often experiencing social rejection, and implied how the particular image of people with ID may be influential in evoking a particular emotional response and behavioural intentions. Moreover, this emotion-evoking potential was more influential in predicting social acceptance or rejection than reported previous contact. This may indicate that emotions are important in predicting future contact (or avoidance), and this notion is gaining attention in the contact-attitude literature (Brown & Hewstone, 2005; Dijkster & Koomen, 2007). Emotions such as anger and anxiety were not only associated with potential neighbours' desire to reject people with ID as new neighbours, but also with their need for particular preparatory actions, such as the possibility to exercise control over who moves in the property next door, or whether they would be allowed to move in at all. Moreover, and in line with previous findings (cf. Bos et al., 1999; Crandall & Moriarty, 1995; Hewstone et al., 2002; Schlueter & Scheepers, 2010), these emotions were influenced by manipulations of group size and severity of ID of the people moving in, and

were also associated with specific interaction needs after the initial move. For example, people would prefer to solve problems with staff rather than with a neighbour with ID in case of a larger home for people with severe ID. Conversely, pro-social emotions, typically aroused by social groups perceived as vulnerable or sociable, were associated with pro-social behavioural intentions. Potential neighbours experiencing these emotions were more likely to accept people with ID as neighbours, less likely to need control in the preparatory phase (though some preparatory action was still desirable), and more likely to engage in further contact, such as volunteering. These pro-social emotions, also, could be manipulated by group size and severity of ID; a smaller group of people with mild ID moving into a neighbourhood was related to stronger pro-social emotions.

Actual interpersonal contact

Furthermore, in studying actual interpersonal contact between neighbours with and without ID (see chapter 4 and 5), we gained insight into the ways in which neighbouring with people with ID in small scale care facilities appeared to be either congruent or incongruent with what was perceived as 'normal' neighbouring. Specifically, we found that typical neighbouring called for a balance between superficial politeness and a readiness to help each other out when needed on the one hand, and keeping one's distance on the other hand (e.g. Forrest & Kearns, 2001; Stokoe, 2006; Unger & Wandersman, 1985). Yet, neighbouring with people with ID sometimes made these superficial exchanges special. For example, the interference of a formal care organisation occasionally gave neighbouring a business-like character, different from the personal character typical of neighbouring with residents from a private dwelling. Not only neighbours without ID sometimes took notice of this, the people with ID involved in our study also indicated how a care organisation (perhaps unwittingly) intervened in neighbouring interactions, a factor often mentioned in other (neighbourhood) integration studies (e.g. Abbott & McConkey, 2006; Todd, 2000). Additionally, people with ID themselves sometimes asked for more tolerance or involvement from neighbours than could be expected in a typical neighbouring relationship.

Taking these results together, it seems essential to correctly interpret neighbours' reactions in order to understand and improve social integration, and, for example, understand that different reactions may have their basis in different thoughts and emotions, without necessarily being a sign of stigmatisation or general malice. In addition to that, it seems valuable to pay

detailed attention to the way in which daily interaction between people with and without ID answers to their mutual neighbouring needs.

Methodological issues and future research

Our approach to neighbourhood social integration, focussing on interpersonal contact from a social psychological perspective, has given us an insight into the minds and behaviours of neighbours with and without ID at a pre-contact and contact stage. Below we outline the strong and weak points in our approach, and look towards ways in which these can be addressed in future research into neighbourhood social integration of people with ID.

Studies at the pre-contact stage

Our pre-contact studies involved a representative sample of members of the general public, who anticipated interpersonal contact with people with ID in a neighbourhood setting. Using an internet survey in studying people's responses to the hypothetical situation of people with ID moving into one's neighbourhood allowed us to design a pre-contact stage in a semi-experimental fashion. This way, we could compare social responses to people of different marginalised groups whilst keeping other factors relatively constant. Additionally, we could systematically manipulate both group size and stigma severity. As of yet, no such approach has been taken in studying the different motivations behind social acceptance or rejection of different social groups in a neighbourhood setting.

However, a downside of using a hypothetical situation is that our behavioural outcome measures necessarily refer to intentions rather than actual behaviour. The gap between intentions and behaviour in related research into neighbourhood social acceptance of people with ID is well known (e.g. Okolo & Guskin, 1984; Overkamp, 2000). It might be necessary to repeat our study approach in a longitudinal setting, in which neighbours' specific emotions and actual behaviours are followed over time to draw further conclusions about actual behaviour.

Another limitation in our pre-contact studies may be the lack of attention to the possible influence of background demographics of the study population; e.g. whether people from relatively quiet vs. build-up areas engaged in different types of neighbouring, and how this may relate to anticipating neighbouring with people with ID. While our study was not designed with the intent to unravel all the different aspects of neighbouring in different localities (see for instance the recent works of Linders (2009) and Vermeij and

Mollenhorst (2008), for elaborate studies on Dutch neighbourhood social networks and neighbouring), future research may benefit from taking some of these factors into account as covariates when looking into the specifics of neighbourhood responses to people with deviant characteristics.

Finally, the relationship between contact, emotional responses and behavioural intentions could be further examined in a longitudinal setting. From the literature on the contact theory (Crisp & Turner, 2009; Pettigrew & Tropp, 2006), and also from past research into neighbourhood responses to people with ID (Arens, 1993; Barr et al., 2003; Hudson-Allez & Barrett, 1996), contact (real or imagined) is related to (general) attitude adjustment and social acceptance. However, we found that emotions, more than past contact, were better predictors of variations in future contact acceptance. This may indicate that contact with persons with considerable differences in appearance or behaviours, while improving general attitudes, may have different effects on specific thoughts and emotions. Furthermore, people may also respond differently to people with ID over time due to a dual process of immediate and implicit emotions when anticipating contact which may later be adjusted by rule-based responses. Pryor et al. (2004) propose that people may often initially respond to stigmatised individuals in an instantaneous, reflexive or associative way and later moderate their reactions with controlled responses based on social rules (motivated by a desire to be politically correct, perhaps). This dual-process model of responding to deviance may be relevant when comparing specific thoughts and emotions when anticipating contact with people with ID to those in actual contact situations, and their related action tendencies in terms of approach or avoidance. A longitudinal study into the effects of past contact on future contact acceptance, with attention to specific changes in implicit and explicit emotional responses, may help understand more about the specific role of emotions in the contact-attitude relationship.

Studies at the actual contact stage

In the second part of this thesis, neighbourhood social integration was further studied by interviewing both neighbours with and without ID experiencing actual social contact. This approach gave us a first glimpse of what social integration means to the people daily involved. By engaging in conversation rather than employing a pre-formulated neighbouring questionnaire based on our own assumptions, we could examine and do justice to the specific details and lived experience of neighbouring between people with and without ID.

While people with ID themselves are increasingly involved in research (Barr et al., 2003; Cardol et al., 2007; Knox, Mok & Parmeter, 2000; Tuffrey-Wijne,

Bernal, Butler, Hollins & Curfs, 2006), their participation is still relatively rare. This may be understandable, as research with people with ID may have its own complications (such as problems with validity and recruitment, e.g. Antaki & Rapley, 1996; Becker, Robert, Morrison & Silver, 2004; Lennox, Taylor, Rey-Conde, Bain, Purdie & Boyle, 2005; Rodgers, 1999), and necessarily our own research may have run into similar problems. For example, we could only include people with mild or moderate ID, while in a recent study by Hubert (2009), it was shown how important it is to include people with severe and profound levels of ID too; their experiences are particularly hard to come by, and may be profoundly different from those of people with mild ID. Conversely, neighbours of people with severe or profound levels of ID may also have different reactions to interacting with them, as is already hinted at in our study. Future research into neighbourhood social integration should include the experiences of people with severe and profound ID too, as it seems likely that their experiences and needs are different from the experiences and needs of the people we interviewed.

Finally, similar to our pre-contact studies, in our studies involving neighbours with and without ID during daily interactions, we could not further examine whether background factors were influential in neighbouring, and to what degree. Instead, our purpose was to get a first picture of what goes on in neighbourhoods in which neighbours with and without ID interact. However, future research may take other factors into account. For example, the neighbours without ID who participated in our study seemed of a rather similar background (suburban, white, middle-class), which suggests a homogeneous and self-selected group. Yet, as their experiences varied greatly, this may not have been such a big problem in coming to a first glimpse at how interpersonal contact between neighbours with and without ID worked. In further studying this, however, it is necessary to involve people from more backgrounds, if only to see if other factors play a part in determining baseline neighbouring, and how this may make neighbouring people with ID different. In interviewing people with ID, we likewise did not examine whether other factors such as their age, personality, level of support needs or years of institutional living influenced their experiences. These factors may play a role in neighbouring experiences, both for people with ID as well as for the neighbours with whom they interact, and previous studies mentioned in the introduction have already hinted at this (e.g. Arens, 1993; Graham & Hogan, 1990; Schwartz & Rabinovitz, 2001; Wilmoth et al., 1987). These factors may be better examined in further research, employing a longitudinal design and

using quantitative outcome measures focussing on specific thoughts, emotions and interaction needs.

Practical Implications

From our study results, we may conclude that neighbourhood social integration requires a balancing act of matching the (perceived) needs of both neighbours with and without ID. Improving relationships between people with ID and their neighbours, to a degree that mutual needs are met, may in fact enhance the quality of life of people with ID. Of course, we still need to learn a lot more about the detailed causal relationships between trait attributions, emotional responses and neighbouring interaction needs, and about the particular roles of other mitigating factors (such as contact experience, demographics or personality and support needs of people with ID). Nevertheless, at two stages in the social integration process, when neighbours anticipate interpersonal contact with people with ID, and later when neighbouring between people with and without ID becomes an actual everyday experience, particular actions may be taken by a care organisation and its staff in order to anticipate and meet these needs.

Anticipating and understanding initial neighbourhood reactions

A care organisation planning to move people with ID into a neighbourhood should be aware that neighbours may have particular emotional responses and concerns about the impending arrival of neighbours with ID in their immediate environment. Rather than dismiss these concerns as evidence for stigmatisation or unfair social rejection, it is important to recognise the variability of social responses to people with ID and understand their underlying motivations in order to include future neighbours as allies in the integration process (Cook, 1998). An autonomous approach to facility siting, keeping a low profile during the siting process, focusing on consumers' rights, and seeking support from legislation, is not uncommon (reasoning that "You didn't seek permission to move into this neighbourhood, so why should we?" Dear, 1992, p. 294). However, with our studies on the anticipation of having neighbours with ID in mind, it may be more appropriate to pay attention to neighbourhood responses, as they may provide more possibilities to actually improve social acceptance at the pre-contact stage.

Compared with other social groups frequently experiencing social rejection, potential neighbours had an ambivalent perception of people with ID; involving both positive trait evaluations such as high vulnerability and

sociability of people with mild ID, as well as dangerousness in the case of people with severe ID. This meant that while neighbours often felt sympathy for having people with ID as neighbours, they could also experience some anxiety and anger, especially when it concerned a large group of people with severe ID. These emotions influenced neighbours' intention to socially accept or reject neighbours with ID and were also associated with a need for particular preparatory actions prior to the move. For example, a care organisation may need to be aware that potential neighbours who feel threatened and experience anger at the prospect of people with ID becoming their new next door neighbours may need to experience some control over the process (e.g. through anonymous voting or choice over particular residents). Allowing extensive control (e.g. voting), of course, is not possible, as it infringes the rights of people with ID to live in the neighbourhood of their choice, and one may question whether allowing potential neighbours any control at all is actually beneficial for other relocation projects. Nevertheless, ignoring this desire for control may lead to harsher social rejection, contact avoidance or stigmatisation at a later stage (cf. Zippay, 1997), as neighbours are unable to satisfy their needs (Dijker & Koomen, 2007). Perhaps, a care organisation can curb these negative responses and generate more tolerance by allowing some level of control to potential neighbours. Possibly, having some say in staffing hours, receiving a phone number in case of concerns, or being involved in periodical feedback moments regarding the home, would provide enough of a sense of control over changes in one's neighbourhood to generate tolerance. This may represent a tension in which the interests and rights of two groups seem to be diametrically opposed. However, it may be possible to be respectful of the needs of both parties, in order to improve social acceptance and general benevolence.

The needs of potential neighbours who are more anxious or concerned, are perhaps not to be confused with those that are angry. While anxiety was also related with a desire for control, and a care organisation can thus offer similar opportunities for control as mentioned above, potential neighbours who felt anxious were more open to information about new neighbours with ID. This may provide care organisations with more opportunities than just involvement in decision making, as they may choose to provide information about various aspects of the home and its residents instead. Perhaps, tailoring this information to the specific fears and concerns of potential neighbours would be even more beneficial, although more would need to be known about the exact sources of these.

Potential neighbours who make positive trait attributions about people with ID, and report sympathy about them becoming next door neighbours, may on the surface provide care organisations with the most possibilities for social integration. Sympathetic neighbours seemed to have less desire for control and presumably would not need to be as involved in the relocation process as anxious or angry neighbours. However, even with sympathetic neighbours, it may be unwise to completely refrain from any preparatory action. As sympathy was associated with a desire for an open house, a care organisation can organise these to let people with ID and their potential neighbours get acquainted; an approach that may be too premature for anxious or angry people.

Being aware of specific neighbourhood responses and undertaking appropriate preparatory action may be even more relevant when care organisations are planning to house a larger group of people with severe ID in neighbourhood housing facilities. Nevertheless, in these cases, a care organisation may need to anticipate stronger reactions and recognise that the need for appropriate neighbourhood preparation prior to the move is all the more necessary, despite what may be politically desired.

Matching mundane neighbouring needs

After people with ID have moved into a neighbourhood, and interactions with neighbours without ID become an everyday occurrence, a care organisation may still improve neighbourhood social integration by facilitating and mediating neighbouring between people with and without ID when appropriate. Our study results indicate how people were actively trying to balance their particular neighbouring needs in general with the perceived neighbouring needs of their neighbours with ID. Sometimes, this balance was easily achieved when neighbouring needs of both parties seemed to be fairly alike. However, sometimes neighbouring needs were perceived to be dissimilar, and this made neighbouring with people with ID special. A care organisation may thus need to be aware of normal neighbouring in the particular neighbourhood in which a home for people with ID is located in the first place. Together with an awareness of the neighbouring needs of the people with ID they care for, they may recognise when intervention may be appropriate to help converge the two, or recognise when intervention is undesirable, as neighbouring between people with and without ID seems to have achieved a fair balance. Our results pointed at three possible features of neighbouring between people with and without ID of which care providers

and staff may need to be aware when they are trying to improve neighbourhood social integration.

First, it appeared that both people with and without ID appreciate the casual and superficial neighbouring that seems to be typical of modern neighbourhoods. Care organisations should thus not underestimate the value attached to these mundane interactions, and may need to take measures to facilitate these. Examples of these interactions were greeting familiar faces and exchanging small talk and small favours. Interestingly, while these small superficial interactions were often thought inconsequential; the *absence* of the same would actually often be undesirable and be seen as mildly annoying, or even rude. Moreover, in the pre-contact studies, minimal and superficial contact seemed to be the single acceptable form of social interaction for people initially feeling angry at the prospect of getting neighbours with ID. With this in mind, a care organisation may improve social integration by facilitating and creating opportunities for people with ID and their neighbours to engage in superficial neighbouring. This includes an awareness of the habits that may unwittingly decrease the opportunity for casual interactions with others in a neighbourhood. Examples of these are the tendency to organise outings for people with ID in group form, use of specialised services for (house) work or social activities, and a high turnover in staff or residents without introductions. These introductions involve informing neighbours about moving plans, formal open days, but also informal introductions of new residents or staff members may continue to be necessary at later stages. The physical appearance of a home may also contribute to decreased possibilities of casual interactions; lack of a garden or driveway, or the existence of a high fence or wall may obscure people from view and limit opportunities for becoming sufficiently familiar for greetings or small talk (for a studies into the importance of common open spaces for casual interactions and social ties in neighbourhoods, see Kuo, Sullivan, Coley & Brunson, 1998; Skjaeveland & Garling, 1997). Small favour exchange may also improve with staff facilitation. Neighbours without ID hesitated asking for a favour from their neighbours with ID (sometimes thought to be incapable to provide assistance), or their possibly overworked staff. Providing favours was sometimes thought equally difficult either by the formality and efficiency or care around a home for people with ID, which meant that small tasks were already taken care of. Here, also, a care organisation may be able to lower the threshold. For example, offering the occasional favour that may suit the capabilities of the residents (e.g. bring empty bottles down the bottle bank), or occasionally asking for a small favour

without automatically referring to their own organisational resources (e.g. the proverbial cup of sugar).

Another factor, of which care organisations may need to be aware, is the role of mediator they are often assigned to by both neighbours with and without ID, especially in instances when neighbouring needs seem dissimilar, or interactions are strained. Both neighbours with and without ID sometimes express being insecure in meeting the other person; being unaware what the needs and capabilities of the other party are, and how one is to adapt to them. Interactions between people with and without disabilities are often strained because of mutual insecurities (Hebl et al., 2000) and staff may help in these exchanges; both when a mutual need to understand the other person is needed, and when mediation to solve a problem is necessary. Especially in conflict situations, the role of staff as mediator may become important. For people with ID, staff may already be an ally to solve problems such as neighbourhood harassment or teasing, but also for their neighbours, staff may be a first port of call when problems need to be solved. People with ID, especially people with severe ID, may be seen as less accountable for, for example, noise or intrusive behaviours. While this may generate some extra tolerance, as they are perhaps not entirely to be blamed, this tolerance may become strained over time and neighbours without ID may still need a person responsible to solve their problem. Note that in the pre-contact studies, potential neighbours of larger homes for people with severe ID were especially likely to rather approach staff than residents for problem solving, underlining the importance of staff as mediator. Staff may not recognise themselves in this role, technically not living in a neighbourhood themselves. Moreover, their workload and multiple responsibilities in the care provision for the residents can possibly leave them unwilling or insufficiently supported to work on social integration (Kröber, 2008) and thus engage in neighbouring. However, it may be likely that mediation can not only solve minor neighbourhood conflicts and generate future tolerance, but also possibly prevent major conflicts. While the manner in which staff are best to mediate in neighbourhood conflicts still needs to be further studied, it seems reasonable that the more personal approach (as opposed to the formal approach perhaps favoured by organisations) may be more promising; solving a problem with a single, identifiable, approachable and responsible neighbour may be easier than a faceless organisation (or too many faces representing a variety of formal positions) not part of a neighbourhood at all.

It also seems important for staff to recognise what interactions can be considered part of typical neighbouring (and may thus be improved by

facilitation or mediation), and what may be going beyond. For some people with ID, neighbourhood relationships only seemed to count when they involved structural activities with people in a formal relationship (i.e. volunteers). For example, walking the dog together or taking a neighbour with ID out for shopping trips were activities often arranged at set time schedules, departing from the spontaneous and casual domain of typical neighbouring. Volunteer relationships may call for an entirely different set of motivations and requirements (which may allow for less reciprocity in a relationship and require support and recognition within a formal structure, e.g. Hidalgo & Moreno, 2009; Jameson, 1998; Taylor & Bogdan, 1989) than merely engaging in appropriate neighbouring. Repeated intensive interactions, such as (bi-) annual barbecues or neighbourhood walks, may also be perceived as over-involved neighbouring, and may suffer from a drop of interest after the first occasion. Before suggesting such activities, staff may need to be more aware of the kinds of contact which may go beyond the typical superficial and convivial neighbouring in their particular neighbourhood, and which likely ask too much involvement of neighbours. Moreover, it may even be less wise to suggest activities like this to people who feel anxious or even angry at the prospect of contact with people with ID. In these cases, neighbours may be more interested in keeping their distance with superficial or minimal contact, and forcing more interaction may be counterproductive (e.g. cause more fear or contact avoidance). Staff may be more successful offering these activities to sympathetic people, who are more likely to want both a relationship based on reciprocity and care, provided these activities fit the typical neighbouring in their neighbourhood. Examples may be invitations for short visits, occasional help, and even walking the dog, provided these activities are not structural or contractual.

While neighbours can be an important contributor to well-being, they play a specialised role in each others' social network (i.e. the role of neighbour), and may thus not be the best sources for intensive (care) relationships, should those be desired. Nevertheless, care organisations may take some particular actions to smooth not only possible negative reactions to the relocation of people with ID, but also continued neighbouring between people with and without ID, provided they can shed some institutional habits (Hamlin & Oakes, 2008; Kröber, 2008; Overkamp, 2002) and think more like neighbours. This may be hard, as a care organisation may initially (and naturally) be more concerned with the needs of the people they care for. However, the main objective, of course, would be to see whether our suggestions may contribute to the

improvement of neighbourhood social integration, and by doing so ultimately improve the quality of life of people with ID.

Concluding thoughts about neighbourhood social integration

We started our thesis by describing the tendency of public debate to focus on limited social integration of people with ID from a personal or political perspective, often on the basis of unclear goals and definitions. With the results of our study, however, we tried to say something about the possibilities of improving social integration of people with ID in neighbourhoods: both at a pre-contact stage when plans for a small scale care facility are formed and during continued daily interactions after the move.

Firstly, it seems important to understand that not every negative social response is evidence for stigmatisation or social rejection and not all positive responses evidence for social acceptance. These responses may be motivated by different perceptions of people with ID and are related to different emotions and needs. There are important differences in the way in which future neighbours may respond to having people with ID as neighbours, motivating a variety of different behaviours beyond mere acceptance or rejection. This presents care organisations with many possibilities to improve social integration of their clients; provided they anticipate the differences in these reactions, know what future neighbours think and feel, and are willing to take them seriously with tailored education or other preparatory actions.

Secondly, successful neighbourhood social integration may be achieved when the mutual neighbouring needs of both people with ID and their neighbours are satisfied. This may imply merely engaging in superficial and casual neighbouring, but may also call for occasional adaptation either by people with ID, their staff, or their neighbours, in an effort to meet each others' needs. However, when more intensive social contact and relationships are desired by people with ID, it may make more sense to invest in these relationships in other social contexts beyond the immediate neighbourhood. So-called 'communities of interest', where community members may have shared interests and participate on a more voluntary basis, may provide better opportunities for involved contact and social relationship development. Examples of these may be hobby groups at neighbourhood centres, church groups and social or sports clubs, but maybe also social activities organised for people with ID themselves (Bolsenbroek & van Houten, 2010; Duyvendak & Verplanke, 2010). Nevertheless, aims at integrating people with ID in existing social groups with shared interests in various contexts, may also benefit from

the study of social interactions of people with and without ID with detailed attention to specific responses in terms of emotions and interactions needs.

The variety of neighbourhood responses prior to people with ID moving in, and the need to match neighbouring needs of both people with ID and their neighbours in the context of a relocation process, may present a difficult dilemma for care organisations concerned with protecting the rights to integration of people with ID. Integration of people with ID in various contexts often presents care providers with a tension between trying to do what feels morally right, and what may be practically feasible (e.g. Clegg et al., 2008; Meyer, 2004; Simpson, 1998). In terms of neighbourhood social integration, the choice is not necessarily between protecting the rights of people with ID at the possible expense of not meeting the needs of neighbours, or giving too much weight to neighbours' concerns at the expense of people with ID. A middle course may be found in supporting both people with ID as well as their neighbours in the preparation process as well as continued support for actual interpersonal contacts between people with ID and their neighbours after the relocation, in order to ultimately improve quality of neighbourhood life.

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Summary

Summary

In the Netherlands, people with intellectual disabilities (ID) are increasingly moving from segregated care in large institutions into small scale care facilities in regular neighbourhoods ('Community Care'). This reflects a change in care policies during the last 40 years that progressively focus on the improvement of the quality of life of people with ID. Community care aims to improve quality of life by normalising the care environment around people with ID. Compared with care in large scale institutions, community care facilities may be better at improving physical and emotional well-being, freedom of choice and self-determination, personal development and social integration. In the introduction of this thesis (**chapter 1**), we briefly discussed the history behind changing care policies for people with ID that led to community care, and outlined the different forms community care takes in practice. Additionally, various quality of life outcomes of community care policies are discussed before moving on to the topic of our study: Neighbourhood social integration of people with ID, which continues to be a point of concern.

This concern mostly revolves around two issues: the opposition often expressed by (potential) neighbours about accepting people with ID in their neighbourhood, and the lack of interest in social contact with neighbours with ID after they have moved in. However, neighbourhood social integration is not only a matter of being generally positive or negative about interpersonal contact with people with ID in one's neighbourhood. Rather than approaching the issue of social integration with preconceived ideas or norms, we take a social psychological approach and study the specific thoughts, emotions and behaviours of both people with and without ID anticipating and during interpersonal contact with neighbours. By paying detailed attention to specific responses towards interpersonal contact, and the possible underlying psychological mechanisms responsible, we hope to learn more about the complex reality of neighbourhood social integration of people with ID.

In chapter 2 and 3, we study the thoughts, emotions and interaction needs of people at a pre-contact stage, that is, the social responses of potential neighbours to people with ID *before* they move into a neighbourhood. This way, we try to gain an understanding of the psychological processes involved in responding to people with ID that may be responsible for accepting or avoiding intergroup contact in the first place. First, the particular image of people with ID is studied by comparing the responses to them with the responses to other social groups often encountering social rejection. Then, we study whether the severity of ID and the size of the group of people with ID

moving into a home, are associated with different responses or interaction needs at this pre-contact stage.

In **chapter 2**, we report on a study in which 555 members of a nation-wide online panel were asked to imagine that a small group of four people of either one of five social groups (elderly people who require extra care, people with mild ID, people with severe ID, economic refugees, and young offenders) would move into the property next door. We examine the specific thoughts people have about these groups, the emotions evoked when imagining interpersonal contact, and related behavioural intentions, in terms of acceptance or rejection of their presence, and interaction needs. We found that the social groups differed in attributed traits and emotion-evoking potential while anticipating interpersonal contact. In particular, people with mild ID and elderly were the most accepted, and young offenders the least as next door neighbours (responses to people with severe ID and economic refugees remained somewhat in the middle). Furthermore, we found that differences in acceptance between these groups could be explained by emotions aroused and less so by differences in previous contact with these groups. Emotions also appeared to be uniquely related to preferred interpersonal relationships. While anxiety and anger were associated with the desire to mostly avoid contact and a need for control in interpersonal relationships; sympathy was associated with a desire for the most social contact (such as caring and reciprocal relationships).

In **chapter 3**, we report on a study which examines the role of group size and severity of ID on social acceptance. Again employing a nation-wide internet panel, we asked 426 people to imagine having either a small (4) or large (12) group of people with mild or severe ID moving in next door. We found that these two factors independently influenced social acceptance and a variety of emotional and behavioural measures. In particular, a large group of people with severe ID aroused the strongest negative responses, and a small group of people with mild ID the weakest. Small groups with a severe disability and large groups with a mild disability aroused similar and intermediate negative responses. Moreover, people also desired less preparatory actions prior to the move of a small group of people with mild ID, compared with a large group of people with severe ID. They were also more likely to further engage with their neighbours with ID (in solving neighbouring problems or doing volunteer work).

In Chapters 4 and 5, we report on two qualitative studies into daily experiences of actual contact between neighbours with and without ID. Asking about their experiences and wishes in terms of everyday neighbouring, we aimed to find out whether actual interpersonal contact between neighbours

with and without ID answered to their mutual needs, and what factors may be involved when those needs differed.

In **chapter 4**, the results of extensive interviews with 39 people with intellectual disabilities living in neighbourhood housing facilities in various neighbourhoods were reported. We found that these people mostly desire superficial neighbouring interactions similar to general neighbouring often reported in modern Western neighbourhoods. However, their experiences occasionally seemed influenced by three factors. Firstly, people with ID felt that staff could mediate (both in positive as well as negative terms) their interactions with neighbours. Secondly, while most people with ID we interviewed appreciated superficial contact, for some, this contact did not seem to count, as more intensive, formal relationships (often on volunteer basis) were sought. Finally, some people with ID occasionally expressed apprehension at meeting strangers in their neighbourhood, or showed a lack of initiative perhaps because of feelings of insecurity.

In **chapter 5**, results were reported of the interviews with 30 people without ID who were neighbours of small-scale care facilities for people with ID in various neighbourhoods. We addressed the neighbours' everyday experiences of neighbouring in general, and neighbouring with people with ID in particular to look for differences and similarities. According to the people interviewed, and in line with our expectations, neighbouring called for a fine balance between showing friendliness and avoiding becoming over-involved. It emerged that neighbouring with people with ID was sometimes experienced to be different, though not necessarily negatively so. Similar to the experiences of people with ID we interviewed, non-ID neighbours also found that the presence of a formal care organisation could intervene typical neighbouring with both positive and negative results. Some examples of this formality were the presence of paid staff, sometimes in high turnover, the arrangement of group activities and formal means of problem solving. Additionally, the interaction style of some of the neighbours with ID occasionally also conflicted with informants' assumptions about neighbouring. Some concerns were expressed about a possible lack of keeping an appropriate distance, reciprocity and accountability among their neighbours with ID, and the possibility and appropriateness of having a superficial neighbouring relationship.

In **chapter 6**, the results of our four studies are integrated in a theoretical framework of the psychological aspects of interpersonal contact between neighbours with and without ID. On the basis of our theoretical analysis, we concluded that regular neighbouring in modern Western society often takes the form of benevolent tolerance, rather than stigmatisation and prejudice. Prior to

getting people with ID as new neighbours, prospective neighbours without ID experience a specific pattern of emotions that are associated with specific desires (e.g. evoked anxiety when anticipating interpersonal contact was associated with a desire for minimal contact and more information prior to facility siting). These anticipatory reactions are dependent on the expected size of the group moving in and on the severity of intellectual disability. Furthermore, while actually engaging in neighbouring, neighbours with and without ID appear to have experiences related to the behaviour of residents, staff, and features of housing facilities, that are perceived as (in) congruent with regular neighbouring. We concluded that interpersonal relationships between neighbours with and without ID should not be simplified in terms of attitudes that would be primarily prejudiced/stigmatizing versus entirely accepting. Rather, our studies paint a more complex picture of sometimes ambivalent thoughts, feelings, and interaction needs that all should be taken into account to make social integration a success.

In the general discussion, **chapter 7**, we further elaborate on the methodological strengths and limitations of our study and offer tentative suggestions for improving neighbourhood social integration. Most importantly, our study approach has resulted in partial understanding of the underlying mechanisms responsible for the different social responses to anticipated contact with neighbours with ID, and of the daily reality of interactions between neighbours with and without ID as expressed in their own words. However, much work still needs to be done in order to uncover more of the specific causal relationships between attributed traits, emotions, and resulting behaviour in interpersonal contact with neighbours with ID. Additionally, various other factors such as the influence of demographic factors of both people with and without ID may need to be included to determine whether they may influence social responses to interpersonal contact.

In spite of the methodological limitations discussed in the final chapter, we have also suggested some ways of improving neighbourhood social integration. First, care providers planning to move people with ID into an existing neighbourhood may expect different responses from neighbours, which may require tailored responses in terms of education, information, an open house, or involving neighbours in some minor decisions. Second, care providers may help matching neighbouring needs of both people with and without ID when necessary, and operate as a neighbour themselves by facilitating and mediating neighbouring interactions. The results of our studies

suggest that by doing so, it may be possible to improve neighbourhood social integration, and thus ultimately the quality of life of people with ID.

Samenvatting

Samenvatting

In de afgelopen veertig jaar is er in Nederland veel veranderd in de zorg voor mensen met een verstandelijke beperking. Woonden zij eerst voornamelijk in grote, afgezonderde instellingen, tegenwoordig wonen zij steeds vaker in kleinschalige voorzieningen in reguliere woonwijken, onder de noemer 'Community Care'. Deze verandering weerspiegelt een ontwikkeling in zorgbeleid, dat zich steeds meer is gaan richten op de verbetering van de kwaliteit van leven van mensen met een verstandelijke beperking. Met community care wil men de kwaliteit van leven van mensen met een verstandelijke beperking verbeteren door het normaliseren van de zorgomgeving. In tegenstelling tot zorg in grootschalige instellingen, zouden de kleinere community care voorzieningen beter in staat zijn het fysieke en emotionele welzijn, de keuzevrijheid en zelfbeschikking, persoonlijke ontwikkeling en sociale integratie te bevorderen. In de inleiding van dit proefschrift (**hoofdstuk 1**), wordt in het kort de geschiedenis achter het veranderende zorgbeleid, waarvan community care het resultaat is, besproken. Ook worden de verschillende vormen van community care in de praktijk geschetst. Daarnaast bespreken we de verschillende uitkomsten van community care op het gebied van kwaliteit van leven en we sluiten af met het onderwerp van onze studie, sociale integratie van mensen met een verstandelijke beperking in woonwijken, wat nog altijd een zorgpunt van community care blijkt.

De problemen rond sociale integratie in woonwijken draaien vaak om twee zaken: de oppositie die (aanstaande) burens uiten alvorens mensen met een verstandelijke beperking in hun straat gaan wonen, en het gebrek aan interesse voor sociale contacten met hen na de verhuizing. Echter, sociale integratie in de woonwijk is niet alleen een kwestie van een algemene positieve of negatieve houding ten opzichte van interpersoonlijk contact. In plaats van sociale integratie te bekijken met vooropgezette ideeën of normen, hanteren we een sociaalpsychologische benadering en bestuderen we specifieke gedachten, emoties en het gedrag van mensen met en zonder verstandelijke beperking, zowel anticiperend op, als tijdens contact met elkaar. Door te kijken naar de specifieke reacties op interpersoonlijk contact en door het uitdiepen van de achterliggende psychologische mechanismen die mogelijk verantwoordelijk voor deze reacties zijn, hopen we meer te leren over de complexe realiteit van sociale integratie van mensen met een verstandelijke beperking in woonwijken.

In de hoofdstukken 2 en 3 bestuderen we de gedachten, emoties en interactiebehoeften van mensen in een precontactfase, dat wil zeggen de reacties van potentiële burens op mensen met een verstandelijke beperking voordat zij in de wijk komen te wonen. Op deze manier proberen we een

inzicht te krijgen in de psychologische processen die een rol kunnen spelen bij het accepteren of afwijzen van deze mensen als naaste buur. Als eerste is het specifieke beeld dat mensen met een verstandelijke beperking kunnen oproepen, bestudeerd door het te vergelijken met de reacties op andere sociale groepen die ook vaak te kampen hebben met sociale afwijzing. Vervolgens hebben we bekeken of de ernst van de beperking en de grootte van de groep mensen die in de woning komt te wonen, een rol spelen in de verschillende reacties of interactiebehoeften in deze precontactfase.

In **hoofdstuk 2** worden de resultaten van een onderzoek beschreven: 555 leden van een landelijk online panel werd gevraagd zich voor te stellen dat een kleine groep van vier personen van één van vijf sociale groepen (hulpbehoevende ouderen, mensen met een lichte of ernstige verstandelijke beperking, economische vluchtelingen en jongeren met een crimineel verleden) zou verhuizen naar de woning naast hen. We onderzochten de specifieke gedachten die mensen hebben over deze groepen, de emoties die het ingebeelde contact met de groep oproep, en de daarmee samenhangende gedragsintenties; dit alles met betrekking tot de acceptatie of afwijzing van hun aanwezigheid en gewenste relaties. We ontdekten dat de sociale groepen verschilden in toegeschreven eigenschappen en opgeroepen emoties als men anticipeerde op interpersoonlijk contact. In het bijzonder mensen met een lichte verstandelijke beperking en hulpbehoevende ouderen werden het meest geaccepteerd als burens; jongeren met een crimineel verleden het minst (reacties op mensen met een ernstige verstandelijke beperking en economische vluchtelingen bleven enigszins in het midden). Verder ontdekten we dat de verschillen in acceptatie tussen deze groepen verklaard zouden kunnen worden door opgewekte emoties en in mindere mate door in het verleden opgedane contactervaring met deze groepen. Emoties bleken ook een unieke rol te spelen bij de voorkeur voor specifieke interpersoonlijke relaties. Terwijl de emoties angst en woede werden geassocieerd met de wens om contact vooral te vermijden en een behoefte aan controle over interpersoonlijke relaties, werd de emotie sympathie geassocieerd met een verlangen naar het meeste contact (zowel in een zorg- als in een wederkerige relatie).

In **hoofdstuk 3** beschrijven we een studie die de invloed van de groepsgrootte en de ernst van de verstandelijke beperking op sociale acceptatie onderzocht. Opnieuw werd een landelijk internetpanel ($N = 426$) gevraagd om te reageren op de komst van ofwel een kleine (4) ofwel een grote (12) groep van mensen met een lichte dan wel ernstige verstandelijke beperking in de woning naast hen. Uit die studie bleek dat deze twee factoren onafhankelijk van elkaar invloed hadden op de sociale acceptatie en een verscheidenheid van

emotionele reacties en gedragsintenties. Een grote groep mensen met een ernstige beperking wekte in het bijzonder de sterkste negatieve reacties op; een kleine groep mensen met lichte beperking de zwakste negatieve reacties. Kleine groepen mensen met een ernstige beperking en grote groepen mensen met een lichte beperking wekten gelijke en intermediaire negatieve reacties op. Bovendien hadden mensen ook minder behoefte om voorafgaand aan de verhuizing op enige manier betrokken te worden als het een kleine groep mensen met een lichte beperking betrof. Dit in tegenstelling tot een grote groep mensen met een ernstige beperking. Respondenten die dachten aan een kleine groep mensen met een lichte beperking waren ook meer bereid tot toekomstig contact met hun burens (bijvoorbeeld bij het oplossen van burenproblemen of het doen van vrijwilligerswerk).

In de hoofdstukken 4 en 5 doen we verslag van twee kwalitatieve studies naar de ervaringen in het onderling contact van burens met en zonder verstandelijke beperking op het gebied van samenleven met elkaar in de woonwijk. Door te vragen naar hun ervaringen en wensen ten aanzien van de algemene dagelijkse bureninteracties, wilden we te weten komen of het interpersoonlijk contact tussen burens met en zonder verstandelijke beperking beantwoordde aan wederzijdse behoeften. Mochten deze behoeften verschillen, dan wilden we weten welke factoren daarin een rol konden spelen.

In **hoofdstuk 4** worden de resultaten besproken van uitgebreide interviews met 39 mensen met een verstandelijke beperking die wonen in woonvoorzieningen in diverse wijken. Daaruit bleek dat deze mensen veelal behoefte hadden aan oppervlakkige interacties met hun burens, vergelijkbaar met gangbare bureninteracties zoals vaker beschreven in de literatuur over nabuurschap in moderne westerse wijken. Hun ervaringen leken in sommige gevallen echter te worden beïnvloed door een drietal meespelende factoren. Ten eerste hadden mensen met een verstandelijke beperking vaak het idee dat het personeel kon interveniëren in hun interacties met burens (zowel in positieve als in negatieve zin). Ten tweede, hoewel de meeste mensen met een verstandelijke beperking die we hebben geïnterviewd, oppervlakkig informeel burencontact waardeerden, leek dergelijk contact voor sommigen niet te tellen. Zij stelden meer prijs op intensiever contact of formelere relaties (vaak vrijwilligers). Ten slotte leken sommige mensen met een verstandelijke beperking terughoudend in het maken van contact met anderen in de wijk, of toonden een gebrek aan initiatief, hetgeen wellicht voortkomt uit onzekerheid.

In **hoofdstuk 5** worden de resultaten gerapporteerd van interviews met 30 mensen zonder verstandelijke beperking: naaste burens van kleinschalige zorgvoorzieningen voor mensen met een verstandelijke beperking in

verschillende woonwijken. We hebben de burens gevraagd naar hun ervaringen met alledaags contact met burens in het algemeen, en met burens met een verstandelijke beperking in het bijzonder, om zo meer te weten te kunnen komen over de verschillen en overeenkomsten. Volgens de geïnterviewden, en in de lijn van onze verwachtingen, werd onder goed nabuurschap een balans tussen vriendelijke belangstelling en het vermijden van bemoeienis en overlast verstaan. Het bleek dat burenscontact met mensen met een verstandelijke beperking soms als anders werd ervaren, maar niet noodzakelijkerwijs op een negatieve manier. Evenals de mensen met een verstandelijke beperking die we interviewden, vonden ook hun burens dat de aanwezigheid van een formele zorgorganisatie op een zowel positieve als negatieve manier kon interveniëren in het contact met elkaar. Enkele genoemde voorbeelden van deze formaliteit waren de aanwezigheid van professionele medewerkers, soms met een hoog verloop, de opzet van groepsactiviteiten en de formele benadering van probleemoplossing. Daarnaast was de interactiestijl van sommige burens met een verstandelijke beperking zo nu en dan in strijd met de opvattingen van de ondervraagden over gangbaar burenscontact. Enige bezorgdheid werd geuit over een mogelijk gebrek aan het houden van gepaste afstand, wederkerige hulpvaardigheid, en verantwoordelijkheid van hun burens met een verstandelijke beperking, en de mogelijkheid en wenselijkheid van een oppervlakkige burensrelatie.

In **hoofdstuk 6** worden de resultaten van onze vier studies geïntegreerd in een theoretisch kader van psychologische aspecten van interpersoonlijk contact tussen burens met en zonder verstandelijke beperking. Op basis van onze theoretische analyse kunnen we concluderen dat algemeen burenscontact in de moderne westerse samenleving vaak de vorm aanneemt van welwillende tolerantie, in plaats van stigmatisering en bevooroordeelning. Voordat men naaste burens met een verstandelijke beperking krijgt, ervaren aanstaande burens een specifiek patroon van emoties die worden geassocieerd met specifieke wensen (als bijvoorbeeld bij het vooruitzicht van interpersoonlijk contact angst werd opgeroepen, dan werd die geassocieerd met een verlangen naar minimaal contact en meer informatie voordat een woonvoorziening werd geopend). Deze anticiperende reacties zijn afhankelijk van de verwachte grootte van de groep en van de ernst van de beperking van de mensen die in de voorziening komen te wonen. Bovendien, wanneer men daadwerkelijk burenscontact heeft, blijken de ervaringen van burens met en zonder verstandelijke beperking met betrekking tot het gedrag van de bewoners, het personeel, en het uiterlijk van een woonvoorziening, af en toe beschouwd te kunnen worden als incongruent met gangbaar nabuurschap. We concluderen

dat interpersoonlijke relaties tussen buren met en zonder verstandelijke beperking niet moeten worden vereenvoudigd tot algemene termen van stigmatiserende/bevooroordeelde dan wel volledig accepterende houdingen. Integendeel, onze studies schetsen een complexer beeld van de soms ambivalente gedachten, gevoelens en interactiebehoeften waar rekening mee gehouden moet worden om de sociale integratie te laten slagen.

In de algemene discussie van **hoofdstuk 7** wordt dieper ingegaan op de methodologische sterke en zwakke punten van ons onderzoek en bieden we voorzichtige suggesties ter verbetering van de sociale integratie van mensen met een verstandelijke beperking in de woonwijk. Het allerbelangrijkste is dat onze studietoepassing resulteerde in een gedeeltelijk begrip van de onderliggende mechanismen die verantwoordelijk zijn voor de verschillende sociale reacties op geanticipeerd contact met buren met een verstandelijke beperking, en van de dagelijkse realiteit van interacties tussen buren met en zonder verstandelijke beperking, zoals ze die zelf verwoordden. Er moet echter nog veel werk verzet worden om meer te weten te komen over de specifieke causale relaties tussen toegeschreven eigenschappen, emoties en het daaruit voortvloeiende gedrag in interpersoonlijk contact met buren met een verstandelijke beperking. Daarnaast kan het nodig zijn diverse andere factoren, zoals de invloed van demografische factoren van zowel mensen met als zonder verstandelijke beperking, in het onderzoek op te nemen om te bepalen of deze ook een rol kunnen spelen in de reacties op interpersoonlijk contact.

Ondanks de methodologische beperkingen die in het laatste hoofdstuk aan de orde kwamen, hebben we ook een aantal mogelijkheden tot verbetering van de sociale integratie in de woonwijk voorgesteld. Omdat zorgaanbieders die van plan zijn om mensen met een verstandelijke beperking te laten verhuizen naar woonvoorzieningen in reguliere woonwijken, kunnen stuiten op verschillende reacties van buren, is een specifieke aanpak vereist op het gebied van informatievoorziening, bijvoorbeeld door het geven van voorlichting, het organiseren van een open huis, of het betrekken van buren bij een aantal kleinere beslissingen. Ten tweede kunnen zorgaanbieders helpen door de wensen van mensen met en zonder verstandelijke beperking beter op elkaar aan te laten sluiten, indien daar behoefte aan is, en door zich zelf op te stellen als een buurman middels bemiddeling en het faciliteren van interacties. De resultaten van onze studies lijken uit te wijzen dat uitvoering van deze voorstellen kan leiden tot verbetering van de sociale integratie, en daarmee uiteindelijk ook tot verbetering van de kwaliteit van leven van mensen met een verstandelijke beperking.

Dankwoord

Dankwoord

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Curriculum Vitae

Curriculum Vitae

Laura van Alphen was born on October 7, 1980, in Berkel-Enschot, the Netherlands. She obtained her secondary school diploma (VWO) in 2000 (Sint Odulphuslyceum, Tilburg), and started studying Health Sciences at Maastricht University in the same year, specialising in Health Promotion. During her final year, she was introduced to the topic of social integration of people with intellectual disabilities and wrote her masters' thesis on the subject. After graduating in 2005, she briefly worked as a research assistant on a project into substance use and sexual behaviour of teenagers at the Department of Health Promotion, Maastricht University. Between 2006 and 2011 she returned to her original topic of interest of social integration and worked as a PhD candidate at the same department. The results of her project are presented in this thesis. During that time, she also worked as a CAPHRI PhD-representative.

